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NATIONAL EVALUATION
MEDICAID SECTION 2176 HOME AND COMMUNITY
CARE WAIVERS

Robert M. Clinkscale, Jr.

Contract No. 500-83-0056
La Jolla Management Corporation

Department of Health and Human Services
Health Care Financing Administration
Office of Research and Demonstrations

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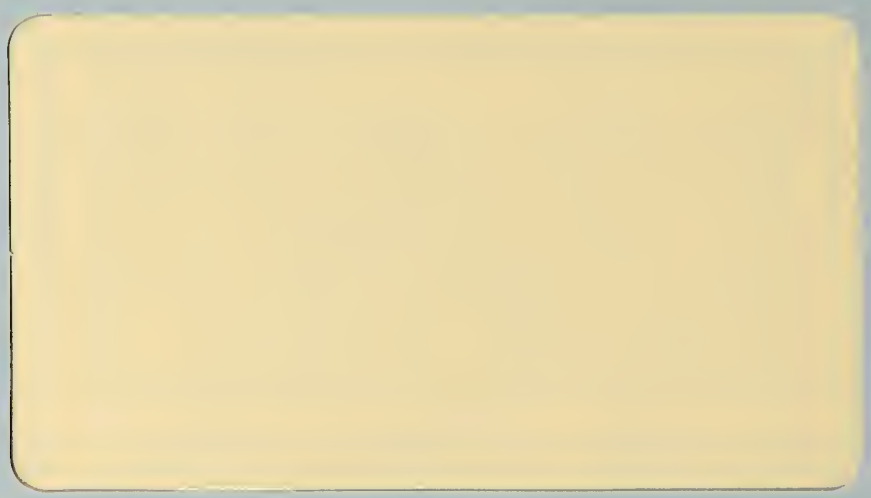

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EXECUTIVE SUMMARY

NATIONAL EVALUATION
EVALUATION OF MEDICAID SECTION 2176 HOME AND COMMUNITY CARE WAIVERS

The Medicaid home and community-based care waiver program operates under the authority of the Omnibus Budget Reconciliation Act of 1981. Under Section 2176, the Department of Health and Human Services may approve waivers to States for Medicaid coverage of certain home and community-based services provided to persons who are at risk of placement in long term care institutions. The home and community-based care waiver, as it is generally known, is an attempt to address an institutional bias in Medicaid eligibility and service coverage policy. Prior to Section 2176, States could not tailor eligibility and service coverage to individuals for which simple home supportive services would have been sufficient. With the Section 2176 waiver, States can use special financial eligibility rules previously available only to the institutionalized and cover home care supportive services such as personal and homemaker care.

The target populations for the Section 2176 waivers are the frail elderly and long-term disabled (A/D) and the developmentally disabled and chronically mentally ill (DD/CMI). The general idea is to realign Medicaid eligibility rules and service coverage so that both the A/D and DD/CMI groups can have equal access to home and residential care as a preferred alternative to long-term institutional care. Home and community-based care is also thought to be less costly than institutional care.

1. EVALUATION OBJECTIVES

In September 1983, the Health Care Financing Administration (HCFA) contracted with La Jolla Management Corporation of Columbia, Maryland to conduct an evaluation of the waiver program. The major evaluation issues were a) how have States used their waiver authority? b) to what extent have States successfully targeted their waivers to individuals who would otherwise be institutionalized? c) have the waivers lowered aggregate Medicaid long-term care expenditures? d) have costs been shifted to other Federal programs? e) are waiver services appropriate and properly monitored? and f) what are the attributes of a successful waiver program? The focus of the evaluation is on both the cost-effectiveness and quality of the State waivers.

The evaluation has investigated the above questions using information reported to the Health Care Financing Administration (HCFA), reviews of prior evaluation research, contractor-initiated annual surveys of State waiver programs, and conduct of six separate case studies of specific waiver programs.

2. FINDINGS FROM NATIONAL LEVEL STUDIES

Three types of national level analysis was conducted. The first was to monitor key operating characteristics of State waiver programs on an annual basis. This was accomplished by conducting annual surveys of all active waiver programs. The second national-level analysis was to conduct a statistical analysis of trends in Medicaid nursing home use and expenditure in States having and not having waivers in order to see if the waivers were associated with any relative reduction in institutional care use or expenditure rates over time. The third use of aggregate data was to analyze annual State reports to HCFA on the implementation status of their waiver programs. The results of these studies is summarized below.

(a) Status of Waiver Program Implementation

The waiver program has been very popular with the States. By September 30, 1986 there were 83 active waiver programs in more than 40 States; 43 A/D waivers and 40 DD/CMI waivers. Approximately 109,628 people were served, 82,981 in the A/D waivers and 26,647 in DD/CMI waivers. Altogether, about $385 million was spent on waiver services, 60 percent of which was spent on DD/CMI waivers. The average annual cost per recipient was $8,281 for DD/CMI and $1,982 for the A/D recipients. For the A/D waivers, most of the funds were spent on personal care and homemaker services while for DD/CMI most of the money was spent on residential care staff and habilitation day programs.

Most people entering waiver programs do not come from institutions, rather they already live at home or in the community and enter the program from that point. Less than 5 percent of A/D recipients enter waivers from nursing homes and only about 35 percent of DD/CMI recipients enter the waiver from an ICF-MR or other institution. Thus, the waiver program has not resulted in an emptying of long term care institutions in any significant way.

(b) Extent That Waivers Have Reduced Medicaid Nursing Home Use or Expenditures

Analysis of data available on State nursing home use and expenditure trends indicates that the waivers have not made a statistical difference on overall national trends for Medicaid-funded nursing home and ICF-MR use and expenditures. This may be because waiver recipient numbers are still relatively small compared with their cohorts still in institutional care. For example, the penetration rate for the A/D waivers has only recently risen to 7.3 percent, the DD/CMI rate is 23.3 percent. The A/D waiver penetration rate is probably too low to make a statistically significant difference in nursing home use rates across waiver States. We were surprised that the DD/CMI waivers made no difference. If the waivers had been successful in reducing ICF-MR use we would have expected to be able to measure the effect. Inspection of national ICF-MR use data indicates that use is on the decline nationwide due to court orders during the mid-1970s to discharge any institutionalized persons who could live safely in less restrictive residential settings. States having DD/CMI waivers did not have rate reductions greater than non-waiver States.

(c) Costs of Waiver Services Versus Institutional Care

Analysis of available State annual reports to HCFA (Form 372) indicated that Medicaid expenditures are lower for waivered clients as compared to cohorts in nursing homes other institutions. Among the reporting States, the average annual total Medicaid expenditure per full person-year of A/D waiver coverage was $8,273 as compared to $12,435 for a year in a nursing home setting. This represents a potential savings of $4,162 per year of coverage; or a one-third reduction.

Data reported for the MR/DD group show greater potential for cost savings; e.g., $11,027 per year for waivered recipients compared to $25,453 per year for ICF-MR residents; a reduction of almost 60 percent per person-year of coverage. Unfortunately, these data were available on only a small number of waivers (eight second year waiver reports approved by HCFA) and may not be completely representative. They do, however, support the notion that home and community care can be considerably less expensive for Medicaid than institutional care.

This analysis of potential savings must be discounted by two considerations. First, several key assumptions must be true before the potential savings will be realized. The general conclusion from prior research and the case studies conducted as part of this evaluation is that these assumptions are not likely to be met. Second, the HCFA Form 372 data has come under some criticism from the General Accounting Office as containing data of questionable validity and reliability. Both of these caveats render our analysis of the Form 372 data of limited value.

3. SUMMARY OF CASE STUDY FINDINGS

The four case studies of A/D waivers in California, Georgia and Virginia suggest that generalizations about how well waiver programs work should be guarded. Firm conclusions can only be drawn from waivers specifically studied. Even then the findings could be flawed given the complexity of the evaluation issues. The A/D case studies (and most of the evaluation research literature) do suggest that client targeting accuracy sufficient to render waiver program budgets neutral to Medicaid is doubtful. There is even some question as to whether the waiver services themselves are appropriate to delay or prevent institutionalization in any significant way. As with any generalization, there are bound to be some exceptions.

The Virginia waiver is a case in point. The Virginia model is to keep the program administratively simple, offer limited services, keep the cost per recipient down, use mandatory preadmission screening, compensate providers for reasonable costs, and employ rigorous quality assurance procedures. The intangible ingredient is to have people everywhere in the delivery system totally dedicated to quality of care. We have learned that these are the determinants of a successful A/D waiver.

The two case studies of DD/CMI waivers in California and Maryland suggest that individuals can be successfully deinstitutionalized. The cost to Medicaid of serving DD/CMI clients is usually considerably less than in ICF-MR institutions. The characteristics of the DD/CMI waiver population suggest that waiver clients are generally younger and less impaired than their cohorts still living in ICF-MRs. It is not clear how effective residential care can be for those cases severely and profoundly retarded. Quality of care in the DD/CMI waivers can be a problem if turnover of residential direct care staff is high. There is also some question as to the real effectiveness of quality assurance models which rely on inspection staff who do not have enough time to get to know the patient personally.

4. GENERAL CONCLUSIONS

It is doubtful if many aged and disabled waivers are cost-effective due mainly to the difficulty with targeting eligibility to individuals who, but for the waiver, would be in nursing homes. This is the conclusion drawn from case studies in California and Georgia. On the other hand, the Virginia case study suggests that linking the waiver program with mandatory preadmission screening for nursing homes may well improve client targeting so that a waiver program can be at least budget neutral to Medicaid. This general conclusion is similar to other evaluation research related to the cost-effectiveness of home care.

As to the cost-effectiveness of DD/CMI waivers, this depends on how one approaches the issue. If States are simply using the waivers to help finance Federal court decrees to deinstitutionalize their large state owned ICF-MR populations, then the DD/CMI waivers in no way could be considered anything but a cost add-on to Medicaid. On the other hand, if the position is taken that the impact of the waivers is to speed up the deinstitutionalization process, waivers having Medicaid per capita costs below equivalent ICF-MR costs will be cost-effective to Medicaid. If other costs of residential care such as SSI payments and food stamps are taken into consideration, cost-effectiveness becomes questionable again. Professionals who administer the waivers are unanimous in feeling that most ICF-MR residents enjoy a higher quality of life in a residential care network where attention is more individualized and emphasis is put on habilitation and maximum independence.

Quality assurance in waiver programs is likely to be very good. Special efforts are made by States to monitor vulnerable individuals very carefully. Case managers are often used to help plan and monitor client progress against structured plans of care. In most waiver programs, clients are reviewed at least every six months and typically seen in their homes at least once a year.

CHAPTER ONE
BACKGROUND AND PURPOSE

This is the final report of an evaluation of the Section 2176 provision of the Omnibus Budget Reconciliation Act of 1981. This provision allows federal financial participation for State Medicaid programs who provide home and community-based care services in lieu of institutional services. This five year evaluation was funded by the Health Care Financing Administration in October, 1983 and was concluded September, 1988.

The general goal of the evaluation is to identify how States used the home care waiver authority and the extent to which Section 2176 waivers resulted in quality services and lower overall Medicaid long-term care costs.

1. HOME AND COMMUNITY CARE IS NOW A SOCIAL PRIORITY

Over the last 25 years institutionalization of the chronically ill and disabled has fallen from social favor. Society has always tended to shun its impaired elderly, physically disabled, mentally retarded and mentally ill into the background. Large public institutions thrived on "taking care" of those who did not have a place in productive society. Since the late 1960s this trend has begun to reverse. Social values now hold that warehousing people in large institutions is no longer affordable, desirable or constitutional. Popular opinion now holds that people are better off living at home and in the community so long as appropriate private and public supportive services can be made available.

Providing long term care services to the chronically impaired in their homes and communities offers an alternative to costly nursing home and other institutional care. Such an alternative may be less expensive than 24-hour residential care and may be preferred by individuals wanting to maintain community ties. Also, workable alternatives to nursing homes and other types of long term care institutions could help meet the increased demand for long term care services expected in the next 20 to 30 years as the elderly population increases dramatically.

(a) The Aging Society

Americans are living longer and healthier lives, and the elderly population is growing at an unprecedented rate. Today, there are more people over the age of 65 than under age 25, a first in U.S. history. Demographic projections indicate significant increases in the number of elderly, from 25 million or 11 percent of the population in 1980, to 45 million or 16 percent of the U.S. population in 2020. More importantly, the population 75 years of age or over increased more rapidly than the population 65-74 years of age. This trend will persist well into the 21st century. The population 75 years of age or older are at much higher risk of chronic disease, disability and institutionalization in a nursing home. Most significantly, current estimates suggest that the most frail elderly, 85 and older, will increase most rapidly; 30 percent during the decade 1990-2000 and 20 percent during the decade 2000-2010. The 85 years or older age group will increase three to four times as fast as the general population.[1]

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[1] Doty, P., Liu, K. and Weiner, J. "An Overview of Long-Term Care" HEALTH CARE FINANCING REVIEW, Volume 6(1):69-78 (Spring) 1985.

(b) Functional Impairments Increase With Age

The 1982 Long-Term Care Survey found that functional impairments increase with age and multiple impairments increase notably only after 75 years of age. Cognitive functioning among functionally impaired persons living in the community appears to remain relatively intact until 85 years of age or over. According to the Survey, only 20 percent of persons 85 years or over were in nursing homes and about 35 percent of persons aged 85 or over who were living in the community were functionally impaired.[2]

The 1984 National Health Interview Survey[3] confirmed findings from the 1982 National Long-Term Care Survey. The 1984 NHIS included a special questionnaire, the Supplement on Aging (SOA), aimed at elderly people living in the community. The survey found that as age increases the amount of difficulty with bathing, dressing, eating, transferring, and toileting increases. For example, less than 6 percent of elderly aged 65-74 had any problems with any activity of daily living. In the 75-84 age bracket about 10 percent had problems. But in the 85 years and over age category 27.9 had difficulty with bathing, 16.6 with dressing, 4.4 with eating, 19.3 transferring, 39.9 walking, 31.3 getting outside, and 14.1 toileting.

Since the risk of chronic disease, disability and dependence on others increases with age, the need for long-term care services is expected to rise dramatically. This eventuality has enormous social and economic consequences. Long-term care refers to a wide range of medical, health related, and social services for persons who, because of chronic mental or physical illness and disability, need personal assistance in caring for themselves over an extended period of time.[4] The majority of all long-term care is provided in the recipient's own home by family and friends.

Long-term care is required for persons with chronic disabilities that impair their ability to perform necessary activities of daily living (ADLs) such as eating, toileting, mobility, bathing and dressing. These services are personal care by nature. On the other hand, a person may simply need help with instrumental activities of daily living (IADLs) such as housekeeping, shopping and errands, food preparation, money management, laundry and chores. IADLs are often used to indicate the ability to live alone. Although the need for long-term care services is concentrated on the frail elderly, others such as the physically disabled, developmentally disabled (primarily the mentally retarded), and chronically mentally ill are also in need of long-term care services.

The discovery of new medical technologies, improved lifestyles and other factors lengthen life expectancy. However, decreased mortality rates may also mean greater prevalence of multiple chronic illnesses characteristic of older age groups. Further, sociologic changes in family structure and increasing numbers of working women may further complicate

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[2] Macken, Candance L., "A Profile of Functionally Impaired Elderly Persons Living in the Community" HEALTH CARE FINANCING REVIEW, Volume 7(4):33-49, (Summer) 1986.

[3] National Center for Health Statistics, D. Dawson, G. Hendershot and J. Fulton: "Aging in the Eighties, Functional Limitations of Individuals Age 65 Years and Over," ADVANCE DATA FROM VITAL AND HEALTH STATISTICS, No. 133, June 10, 1987.

[4] U.S. Department of Health and Human Services, REPORT TO THE SECRETARY ON PRIVATE FINANCING OF LONG-TERM CARE FOR THE ELDERLY, Draft, November, 1986.

mortality and morbidity projections as well as alter the critical supply of informal care provided to the elderly by family members and friends.[5]

(c) Renaissance of Interest In Home Care For the Elderly

Since the early 1970s, government policymakers have been increasingly concerned about the growing numbers of elderly and their reliance on nursing homes for long-term care. This led to a renewal of interest in home and community-care settings based on the proposition that people are happier and function better at home and that home care is much cheaper than institutional care.

During the late 1970s, 15-20 Federally-sponsored demonstration projects were carried out to test the cost and outcome results of offering various community-based alternatives to nursing home care. The evaluation results were mixed. Most of the demonstrations failed to make the case that case management and various in-home supportive services reduced nursing home use.[6] For the most part, the home care programs failed to accurately identify individuals at very high risk of nursing home entry. Any savings which might have resulted from those correctly identified were offset by the cost of serving others who were not, in fact, nursing home bound.[7] A few studies showed positive savings effects. Further, the evaluations failed to show that, other than increased client satisfaction, improvements in functioning, morbidity or mortality were associated with home care services. More recent evaluation research, namely the National Channeling Demonstration and the Medicaid Section 2176 Home and Community-Based Care Waiver Evaluation, generally reinforces earlier evaluation findings.[8]

In 1985, more than half (51.4 percent) of the $35.2 billion spent for nursing home care was paid for out-of-pocket by patients and their families using available funds, support from relatives and sale of assets. Medicaid paid for most of the other half (41.8 percent) while Medicare paid for less than 2 percent. The reason most of the private pay for nursing homes is "out-of-pocket" is the absence of health insurance coverage for long-term care. Given that the average cost of nursing home care is now $22,500 or $62 per day, increasing numbers of elderly and their families are unable to assume the financial burden. Once within a nursing home, their assets are often depleted within 6 months to one year. After this impoverishment process, which often includes the spouse of an elderly person as well, Medicaid becomes a

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[5] Doty, P. "Family Care of the Elderly: The Role of Public Policy" THE MILBANK QUARTERLY 64 (1):34-75, 1986.

[6] Berkeley Planning Associates, "Evaluation of Coordinated Community Oriented Long-Term Care Demonstration Projects," 1984; and Hughes, Susan L., "Apples and Oranges? A Review of Evaluations of Community-Based Long-Term Care," HEALTH SERVICES RESEARCH 20:4 (October) 1985.

[7] See for example, Weissert, W.G. "Seven Reasons Why It is So Difficult to Make Community-Based Care Cost-Effective" HEALTH SERVICES RESEARCH, 20 (4): October, 1985; and Branch, L.G. "Home Care is the Answer: What is the Question?" HOME HEALTH CARE SERVICES QUARTERLY 6 (1): Spring, 1985; and Hedrick, S. and Inui, T. "The Effectiveness and Cost of Home Care: An Information Synthesis," HEALTH SERVICES RESEARCH, 20 (6): February, 1096.

[8] U.S. Department of Health and Human Services, "Evaluation of the National Long Term Care Demonstration," Mathematica Policy Research, Inc., May, 1986; and DHHS, "Evaluation of Medicaid Section 2176 Home and Community Care Waivers," La Jolla Management Corporation, December, 1986.

payor of last resort.[9] This accounts for why Medicaid pays 41.8 percent of all nursing home payments.

This cycle of aging, health impairment, impoverishment and long-term institutionalization is economically and politically unacceptable. Both the U.S. Congress and the American Association of Retired Persons (AARP) have agreed that nursing home care is not affordable or desirable for most elderly individuals. Older persons prefer to remain at home for as long as possible. Strategic long-term care interventions are necessary that assist frail elderly persons to remain in their homes and community settings and to live out their lives with maximum dignity and independence. For less disabled elderly, Continuing Care Retirement Communities, congregate living arrangements, Life Care at Home, and a variety of other concepts represent new opportunities.[10]

More recently, much attention has been put on the Medicare Prospective Payment System (PPS) in terms of its incentives to discharge patients from hospitals "quicker and sicker." This possibility has policymakers even more concerned about the quality of care in nursing homes and of that rendered by home health agencies and other home care providers.

(d) Mentally Retarded/Developmentally Disabled Population

The size of the mentally retarded/developmentally disabled (MR/DD) population is thought to be approximately 3.9 million, or 1.6 percent of the population. Approximately 2 million of these individuals are over the age of 18. The relatively large number of MR/DD individuals under 18 years of age reflects the great number of children identified in their school years as deficient in "age-appropriate" adaptation, many of whom go on to function at "normal" levels in adulthood.

From the 19th century until the late 1960s, care for mentally retarded (and mentally ill) individuals who could not afford private care was delivered by large public institutions. Most spent their entire lives in an institution. Beginning in the late 1960s, gradually public pressure and the courts began to see this institutionalization as a form of undue restraint and a violation of Constitution rights. States were ordered by the federal courts to deinstitutionalize residents to less restrictive residential settings and receive habilitation services to promote as independent a lifestyle as the individual was capable.

The Social Security Amendments of 1971 created the Medicaid-funded Intermediate Care Facility for the Mentally Retarded (ICF-MR). Prior to this legislation, States provided the bulk of funding for institutional care. Public institutions could receive Medicaid funding only if they qualified as skilled nursing facilities which created a strong incentive for States to convert institutions for the mentally retarded into medically oriented nursing homes. This was expensive and unnecessary. The ICF-MR program allowed States to receive federal funding for their institutions, without requiring expensive and unnecessary nursing care. The 1974 Amendments provided for Medicaid reimbursement for small, community ICF-MR (15 beds or less) facilities in an effort to stem the tide for delivery of care in large institutions.

During the years following the 1971 Amendment, ICF-MR use and expenditures rose dramatically. ICF-MR recipients grew from 12,200 in FY72 to a peak of 151,200 in FY81.

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[9] U.S. Department of Health and Human Services, REPORT TO THE SECRETARY ON PRIVATE FINANCING OF LONG-TERM CARE FOR THE ELDERLY, Draft, November 1986; and American Association of Retired Persons, "Medicaid's Role in Financing the Health Care of Older Women," December, 1986.

[10] Tell, E. et al. "Assessing the Elderly's Preferences for Lifecare Retirement Options" THE GERONTOLOGIST 27 (4) :503-509, 1987.

Expenditures grew from $92 million in FY73 to $2.17 billion in FY82. Until the early 1980s, expenditure increases were driven largely by States converting existing facilities to ICF-MRs. By 1980 recipient levels peaked and continued expenditure increases were driven by increased costs of operating the ICF-MR facilities. This move was consistent with court decisions requiring States to deinstitutionalize the mentally retarded to less restrictive residential care settings.

By the early 1980s, States were actively involved with transferring the mentally retarded from large State-owned ICF-MRs to smaller community-based ICF-MRs and even smaller residential care homes. Medicaid funding was available for the ICF-MRs but not available for residential care and other home-like settings. In 1981, passage of the Omnibus Budget Reconciliation Act and its Section 2176 home and community-based care provision offered States an opportunity to extend Medicaid eligibility (and funding) to a broad range of persons with developmental disabilities, including the chronically mentally ill. The idea was to encourage States to accelerate their efforts to move people from large institutional settings to as close to a home-like setting as possible. Further, in addition to their supervised residential care, waiver residents would receive comprehensive habilitative services in order to maximize their level of independent living. The States enthusiastically supported the concept.

The great majority of individuals with MR/DD have only mild to moderate degrees of disability. Most live on their own or with relatives and require minimal assistance from public programs. However, an estimated 377,000 people have severe or profound retardation.[11] Although many of these individuals live in various kinds of institutions and other residential facilities, many are living successfully in the community.

The percentage of people with mental retardation residing in various types of licensed care facilities has declined over the past two decades, with the less severely impaired, particularly children, being served in the community. Nevertheless, the 1982 survey carried out by the University of Minnesota found that approximately 250,000 mentally retarded people were still served in licensed care facilities. Despite a growing trend away from large institutions and toward the use of small community-based facilities, almost 180,000 of the individuals in the 1982 survey were in facilities of more than 15 beds, while nearly 110,000 were in facilities having more than 300 beds.

Significantly, those still residing in these large State institutions tend to be the most severely retarded; 57.2 percent had profound retardation and 23.8 had severe retardation. Forty-three percent of the residents suffered from multiple handicaps (including epilepsy, cerebral palsy, emotional handicaps, blindness, and deafness), up from 34.4 percent in 1967. The placement of those with severe disability levels in institutions has caused considerable debate. Some argue that the severely disabled are being discriminated against by being denied access to care in community settings. Others maintain that the severity of these individuals' disabilities requires continuing care in closely supervised institutional settings featuring medical support.

Given that the annual cost of care in many of the large public institutions for the MR/DD population is $75,000 to $125,000 per person per year, and given that many of the individuals progress much better in a more individualized and often far less expensive residential care setting, the trend toward more residential care networks for the MR/DD population is assured.

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[11] Lakin, K., Hill, B., and Bruininks, R. (eds.) AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FOR THE MENTALLY RETARDED (ICF-MR) PROGRAM, Department of Educational Psychology, University of Minnesota, 1985.

2. MEDICAID HOME AND COMMUNITY-BASED CARE WAIVERS

The Medicaid home and community-based care waiver program operates under the authority of the Omnibus Budget Reconciliation Act of 1981. Under Section 2176, the Department of Health and Human Services may approve waivers to States for Medicaid coverage of certain home and community-based services provided to persons who are at risk of placement in long term care institutions. The home and community-based care waiver, as it is generally known, is an attempt to address an institutional bias in Medicaid eligibility and service coverage policy. Prior to Section 2176, States could not tailor eligibility and service coverage to individuals for which simple home supportive services would have been sufficient. With the Section 2176 waiver, States can use special financial eligibility rules previously available only to the institutionalized and cover home care supportive services such as personal and homemaker care.

The target populations for the Section 2176 waivers are the frail elderly and long-term disabled (A/D) and the developmentally disabled and chronically mentally ill (DD/CMI). The general idea is to realign Medicaid eligibility rules and service coverage so that both the A/D and DD/CMI groups can have equal access to home and residential care as a preferred alternative to long-term institutional care. Home and community-based care is also thought to be less costly than institutional care.

First, Section 2176 allowed States for the first time to cover "non-medical" as well as medically oriented services in meeting long-term care needs under Medicaid. For example, services such as case management, personal care, homemaker, adult day care, respite care and transportation could be covered under Medicaid.

Second, States were granted considerable flexibility in determining who is eligible to receive waiver services. In determining financial eligibility for the waiver program, States may apply rules used in determining Medicaid eligibility for nursing home recipients. Specifically, States may use a special income level (the so-called "300 percent" rule) in determining eligibility, and/or waive deeming requirements (counting income of other household members) for applicants who live with a spouse or family members who are not Medicaid eligible.

Third, States may limit eligibility to waiver programs to certain groups. Federal regulations require only that recipients meet level of care criteria for admission to a SNF, ICF or ICF/MR. Waivers can be especially targeted to aged only, disabled only, aged and disabled, mentally retarded, and chronically mentally ill. Eligibility can be restricted to those discharging from acute care facilities only, or from the community at large. States may choose to limit eligibility to certain geographic subareas of the State. States are free to tailor their waiver programs to fit their own particular needs and capabilities for service delivery.

States must, however, manage their waiver programs so that the average Medicaid costs for waiver recipients does not exceed the average costs of individuals maintained in institutions. The waiver program has been very aggressively used by the States. By October 1, 1986 there were 83 active waivers operating in over 40 States, serving close to 110,000 persons, at an annual cost of $386 million.[12]

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[12] Health Care Financing Administration, MPE 1.11, "Survey of Medicaid Home and Community-Based Care Waivers: 1986," Prepared by La Jolla Management Corporation under Contract Number 500-83-0056, December 1987.

3. EVALUATION ISSUES AND OBJECTIVES

The program and policy issues surrounding the Section 2176 Medicaid waivers correspond closely to the evaluation objectives. A synopsis of the issues is provided below.

(a) Issues

Most of the 10 million Americans having serious impairments due to chronic disability or aging are cared for in their own homes by family and friends. For those not having adequate informal support, the usual alternative is financial impoverishment and life in a nursing home. The Medicaid home and community care waiver program uses new Medicaid eligibility and service coverage rules to offer previously unavailable home care services to those who would otherwise have no choice but to resort to a Medicaid-funded nursing home. The intended outcome is to prolong a recipients' ability to remain at home and enjoy better health and life satisfaction.

The major issues for the evaluation are:

1. How Have States Used Their Waiver Authority?

   Of major importance to the Congress and HHS is how States chose to use the Section 2176 waiver authority granted by OBRA 1981. More specifically, what populations were targeted to receive what mix of services? How did States choose to administer their programs and integrate the waivers with other long-term care programs? How has eligibility been determined? What steps do States take to screen and enroll waiver applicants? How is quality of care addressed? Do States implement data systems to effectively manage and study the effects of their waiver programs?

   Data with which to answer most of these issues about waiver program design and operating characteristics was for the most part taken from the results of annual surveys of State waiver programs conducted as part of this evaluation.

2. Client Targeting Effectiveness

   The second evaluation issue relates to the extent to which States were successful at targeting the waiver program to individuals who, "but for" the waiver, would have entered nursing homes. The issue is one of the most critical to the evaluation. If the process of outreach, screening, and assessment does not screen out people who would not enter a nursing home anyway, then the cost of serving those individuals becomes an "add-on" cost to Medicaid and undermines the potential for reduced institutional costs to offset the cost of the waiver program. Congress specifically intended the waiver program to be budget neutral to Medicaid.

   Our examination of the literature on prior research and evaluations related to home and community-based care suggests that high client targeting effectiveness is not within the current state-of-the-art (U.S. Comptroller General, 1979; GAO, 1983; DHHS Channeling Final Report, 1986; DHHS Report to the Congress: Studies Evaluating Medicaid Home and Community-Based Care Waivers, 1984; Branch and Stuart, 1984; Berkeley Planning Associates, 1984; Hughes, 1985; Doty, 1984; Weissert, 1985; Hedrick and Inui, 1986).

   The client targeting issue with the DD/CMI groups is the extent to which persons already living in residential care settings would, but for the waiver services and financing, return to ICF-MR facilities for care. Conversely, would

those deinstitutionalized by court decree be able to survive in the community without waiver services? Another way to frame the issue is the extent to which States did and will continue to deinstitutionalize the mentally retarded with or without financial help from the waiver program? Very little research exists on this issue (Maine,1986; Burwell,1986). Most of the developmentally disabled people served by the Section 2176 waivers are already deinstitutionalized and living in residential settings. Thus, the waivers are less likely to result in decreased institutional care. This does not in any way mean that the waiver services does not improve the quality of life for those individuals living in the community. It simply means that near term Medicaid use rates and expenditures for ICF-MR facilities may not decline as Congress intended.

3. Impacts on Medicaid-Funded Nursing Home Use and Expenditures

The impact of 2176 waivers on use and cost of long term care programs is partly dependent of the extent the waivers target clients effectively, partly on the relative magnitude of nursing homes versus waiver service costs, and partly on the degree that waiver services can delay nursing home entry. In theory, the waiver program should reduce the demand for nursing home beds and lower Medicaid recipient use and expenditures. If there were no other pressures to influence supply or demand for beds the evaluation of waiver impacts would be relatively straightforward. However, the waiver programs are only a small part of the overall context of long-term care within a State.

The first and most obvious difficulty in detecting waiver-induced reduction in nursing home bed usage is the fact that waiver recipients to date are a small fraction of the total long-term care population within a given State. In 1986, the average penetration rate of aged and disabled waivers was 7.3 percent of the Medicaid-eligible aged/disabled nursing home population. Statistical measurement of waiver impacts becomes problematic using State-level aggregate data. The penetration rate for the DD/CMI target group is higher; around 20 to 25 percent. This level of penetration is sufficient to detect waiver impact on the demand for ICF-MR services.

To complicate this measurement problem, there are strong influences within a State's overall long-term care continuum of services to confound measurement of any waiver induced effect on the supply and demand for Medicaid-funded nursing home care. On the demand side some of these external pressures include: hospital and community back-up of patients waiting for nursing home placement, earlier hospital discharges due to Medicare prospective payment, revisions in Medicare and other private health insurance policies, demographic changes, revisions in State policies toward financing and delivery of care to the DD/CMI population, availability of other public and private home and community care services, and changing attitudes of informal caregivers.

On the supply side, State certificate-of-need (CON) can limit supply of Medicaid certified beds and reluctance of facility operators to admit Medicaid patients will cause hospital and community back-up of Medicaid patients waiting for nursing home placement. In this case, the effect of reduced demand for beds caused by availability of waiver services may only have the effect of reducing the length of the waiting line, and have no short-term effect on Medicaid nursing home use or expenditures. In the longer term, depending on State CON policies, the supply of nursing home beds will adjust to market forces.

The effect waivers may have on Medicaid nursing home use and expenditures is, therefore, affected by many factors over which Medicaid agencies have no

control. Attribution of statewide or aggregate reduction in Medicaid nursing home use or expenditures due to a waiver program will be difficult. This is why our evaluation puts emphasis on detection of waiver effects at the person-based level.

4. Cost-Shifts to and From Other Public and Private Programs

This evaluation issue considers the financial impact of the waiver program in a broader context than simply the Medicaid cost of waiver services versus nursing homes. The issue has four parts.

Although home and community care waivers may reduce unnecessary nursing home stays and expenditures, an unwanted effect may be a net increase in State Medicaid expenditures due to increases in the demand for traditional Medicaid hospital, physician and other services. That is, home and community residency in lieu of an institution may result in higher hospital admissions, greater access to physicians and drugs, etc. The new Departmental regulations for Section 2176 require States to consider these spill-over effects when considering the financial feasibility of their waiver programs and the new annual waiver statistical reports (HCFA Form 372) take explicit account of these impacts. Our analysis of limited HCFA 372 data offers no evidence that cost spill-overs offset potential savings from waiver programs. That is, acute care Medicaid costs for waiver recipients are about the same as those for institutionalized cohorts.

The second part of the cost-shift issue is the fact that States have strong incentives to use the waiver program to "re-finance" service delivery previously funded by other State government programs; e.g., Title XX social services block grant, Title III aging services block grant, and State budgets for the developmentally disabled or mentally ill. We consider it quite rational for States to do this. The re-financing can be achieved by simply substituting services previously funded by block grant and State funds and shift the cost to the Federally-matched Medicaid program. This will free block grant resources to be spread over a wider population in need. What States may lose in State-matched Medicaid funds may be more than offset by savings in block grant and State budget resources. DD/CMI waivers contain strong incentives for States to shift costs of State-funded institutions for the mentally retarded and chronically mentally ill to Medicaid-funded waiver services; i.e., a re-financing of the already existing residential care network. There is nothing in the Section 2176 or DHSS regulations to explicitly preclude this re-financing option.

Part three of the cost-shift issue is the potential effect of the waivers on other Federal budgets such as Medicare, Supplementary Security Income (SSI), food stamps, and HUD housing subsidies. This evaluation dealth only with Medicare and SSI spill-overs. Regarding Medicare, the waivers could affect Medicare spending either way. One the one hand, waiver services for dual-eligibles could reduce the demand for Medicare-funded nursing home care. On the other, living at home or in the community might increase Medicare inpatient and physician costs. A study of the California Multipurpose Senior Services waiver (aged and disabled) indicated that Medicare was largely unaffected by waiver participation (Miller, L., Evaluation of MSSP - 1981-82, Berkeley,1984).

The last part of the cost-shift issue involves the possible supplantation of private caregiver support with the new availability of home and community care waiver services. Given the extreme burden borne by many caregivers the new availability of home care services may induce caregivers to shift their burden to waiver-funded providers of care. The literature does not support this

argument (Soldo, 1983; Miller, 1984; Berkeley Planning, 1984; Mathematica, 1986). There is evidence that respite care strengthens and lengthens a family caregiver's capacity to continue care, although most caregivers decline needed respite care for emotional reasons (University of California, San Francisco, 1984). Although services provided by private voluntary organizations such as United Way may be supplanted by public-funded waiver services, we know of no studies that show evidence that this actually happens.

6. Quality of Waiver Services

Over the years some consensus has developed as to some basic structural and process quality standards appropriate for institutional care. Very little is understood about equivalent standards for home care. One of the issues for this evaluation is to find out what some of the home and community-based quality issues are and how States go about quality assurance in their waiver programs. The general issue is, "Are States taking appropriate quality assurance measures to ensure that waiver recipients are safe and that the waiver services are appropriate to meet recipient needs?"

7. Attributes of Successful Waiver Programs

What are the attributes of a successful waiver program, in terms of both quality and cost-effectiveness? This last evaluation issue represents a summation of findings in terms of how the waiver program might be improved. The scope of the issue ranges from what has been learned about the determinants of effective administrative models, client targeting criteria and strategies, optimal service mix, exemplary case management and preadmission screening models, relative costs of services, cost-effectiveness, cost-shifting to and from other programs, and which types of waiver programs are associated with desired outcomes. The evaluation final report will report any practices that States feel are particularly exemplary.

The above evaluation issues are difficult and will not be completely resolved by this evaluation. The findings support some of the issues and refute others.

(b) **Evaluation Objectives**

In September 1983, the Health Care Financing Administration contracted with La Jolla Management Corporation of Columbia, Maryland to conduct an evaluation of the waiver program. The major evaluation issues were a) how have States used their waiver authority? b) to what extent have States successfully targeted their waivers to individuals who would otherwise be institutionalized? c) have the waivers lowered aggregate Medicaid long-term care expenditures? d) have costs been shifted to other Federal programs? e) are waiver services appropriate and properly monitored? and f) what are the attributes of a successful waiver program? The focus of the evaluation is on both the cost-effectiveness and quality of the State waivers.

The objectives of the evaluation include documenting how States have used their waiver authority, monitoring State progress towards implementation, and assessing the impact of the waivers at the national, State and recipient levels. A major evaluation issue is to determine the extent to which the waiver services are cost-effective to Medicaid and the possible cost consequences for other Federal programs such as Supplementary Security Income (SSI) and Medicare. In this context, the term cost-effectiveness is taken to mean the extent to which waiver services are effective substitutes for nursing home settings so that the costs of the waiver services is offset by the savings in nursing home or other institutional Medicaid expenditures. A major goal of the evaluation is to find out what determines the success of

some waiver programs and how others might be improved. Finally, the evaluation may provide clues as to how the overall long-term care financing and delivery system might be reformed for the future.

4. OVERVIEW OF RESEARCH METHODS AND DATA SOURCES

An evaluation as comprehensive as this relies on many research methods and data sources. Several evaluation perspectives have been taken, each having unique issues and data sources. At the national level, the emphasis has been on documenting the way States have used their waiver authority, e.g., changes in eligibility rules and service coverage. In addition, emphasis was placed on detecting any reductions in the rate of increase in State and national Medicaid nursing home use and expenditures that may be reasonably attributable to the waiver programs. Major waiver target populations such as the elderly and disabled versus the developmentally disabled/chronically mentally ill are examined separately.

National level research methods and data sources are as follows:

- Multiple regression analysis of the relationships between State Medicaid nursing home use and expenditure trends between waiver and non-waiver States, conducted for each of the two major target populations. Data sets used for this analysis were annual (HCFA 2082), quarterly (HCFA 64) data reported by the States to HCFA, and special survey data. This analysis was conducted once for data through FY85 and again for data through FY86.

- Annual surveys of State waiver programs using detailed written questionnaires to gather data on waiver population characteristics, service mix and costs and quality of care safeguards. These data were not available from routine HCFA data sources, thus were collected specifically for this evaluation. Three annual surveys were undertaken.

- Statistical analysis of annual State waiver reports to HCFA (Form 372). These reports provide basic information as to the number of waiver recipients served, services provided, and costs of services compared with institutionalized populations not served by the waiver. This analysis was undertaken only once due to questions about the validity and reliability of the data reported.

In addition to the above, six case studies were undertaken of State waiver programs. The case studies were needed to address evaluation issues such as targeting effectiveness, cost-effectiveness and quality assurance.

The six case studies were: California Multi-Purpose Senior Services Program (MSSP), California In-Home Medical Care (IHMC) Program, Georgia Community Senior Services Program (CSSP), California Developmental Disabilities (DDS) Program, Virginia Personal Care Waiver Program, and the Maryland Developmental Disabilities waiver. These waivers were selected for analysis because data were available and the States expressed a willingness to cooperate in the case studies. Several site visits were made by evaluation teams to learn about program administration, targeted populations, services provided, quality assurance mechanisms, and screening and assessment criteria. The case studies also represent a cross-section of major waiver populations including the frail elderly, the physically disabled, and the developmentally disabled.

In all cases the availability of data on strength of informal support was very limited. Since strength of informal support is a key determinant in risk of institutionalization, our analyses of the risk determinants of institutionalization is limited. Data on the use of other

public support programs such as Medicare, SSI income security, and block grant social services programs was likewise limited.

5. ORGANIZATION OF THIS REPORT

Chapter One has presented background to the Section 2176 waiver program including the emerging social preferences for home and community-based long term care, an explanation of the Section 2176 waiver program, study issues and objectives and study methods and data sources. Chapter Two contains a summary of findings from annual surveys of State waiver programs. Most of the findings relate to the most recent survey for federal fiscal year 1986. Findings are organized in terms of how States target their programs, recipient characteristics, service use patterns, and expenditures.

Chapter Three contains summaries of the findings from each of the six waiver program case studies. The details of these case studies are contained in other reports.[13] Chapter Four presents our conclusions based on findings from all aspects of the evaluation. The conclusions are oriented around the six major evaluation questions.

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[13] See Clinkscale, R. and Vertrees, J. EVALUATION OF MEDICAID SECTION 2176 HOME AND COMMUNITY CARE WAIVERS, Interim Report, Medicaid Program Evaluation Working Paper No. 1.10, Health Care Financing Administration, December 1986; Clinkscale, R. QUALITY OF MEDICAID HOME CARE SERVICES IN VIRGINIA, Medicaid Program Evaluation Working Paper No. 1.12, Health Care Financing Administration, May 1988; and Burwell, B. MARYLAND WAIVER PROGRAM FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A CASE STUDY, Medicaid Program Evaluation Working Paper No. 1.13, Health Care Financing Administration, August 1988.

CHAPTER TWO
WAIVER PROGRAM RECIPIENTS, SERVICE USE AND EXPENDITURES

This chapter reports findings with respect to the number and size of the waiver programs, criteria used by States to target waiver services to those in need and characteristics of the waiver populations, especially as those characteristics compare and contrast to cohorts in nursing homes and other institutions. Waiver service utilization and expenditure trends are also presented. After a national overview, the discussion is divided between the two general waiver program target groups - aged and disabled (A/D) and the developmentally disabled and chronically mentally ill (DD/CMI). Findings in this chapter rely on annual surveys of State waiver programs conducted as part of the overall evaluation study. Most of the data reported herein were taken from the fiscal year 1986 survey.[1]

1. NATIONAL OVERVIEW

The Section 2176 waiver programs have been very popular among States as a means to serve more individuals at home and other residential care settings as an alternative to institutional care. In FY86, there were 83 active waivers, an increase of 8 over the FY85 level. There were 43 A/D and 40 active DD/CMI waivers. One or more waivers were active in most States. States believe that home care is preferred by most people and their families. Care at home can also be less costly than a nursing home or other institutional care setting.

In FY86, the 83 waivers served approximately 109,628 recipients of waiver services, of which 82,981 were A/D and 26,647 recipients were DD/CMI. State support for the waiver program is best illustrated by the growth in waiver recipients since the first full waiver year in FY83. Exhibit 1 shows how total annual waiver recipients have grown between FY83 and FY86 for each of the waiver types.

Most A/D waiver recipients were frail elderly with multiple functional impairments while DD/CMI recipients were primarily mentally retarded. Most waiver recipients were slightly less impaired than their cohorts in institutional care. In terms of geographic distribution, over half of all waiver recipients were concentrated in only six States. Even with the waiver programs, most Medicaid A/D and DD/CMI recipients still live in institutions. The size of the Medicaid A/D waiver recipient population is only approximately 7.3 percent of all Medicaid nursing home residents. On the other hand, the DD/CMI waiver population is approximately 23.3 percent of all DD/CMI recipients of Medicaid services. Over 95 percent of DD/CMI recipients are mentally retarded.

Total Medicaid spending for waiver services during FY86 is estimated to be $385 million, up from $257 million in the prior fiscal year. About $220 million was spent on DD/CMI recipients and $165 million on the A/D group. This is because the average annual expenditure per DD/CMI recipient is estimated to be $8,281 relative to $1,982 for the average A/D recipient. Therefore, although DD/CMI recipients are only one-quarter of all recipients, they required close to 60 percent of total spending.

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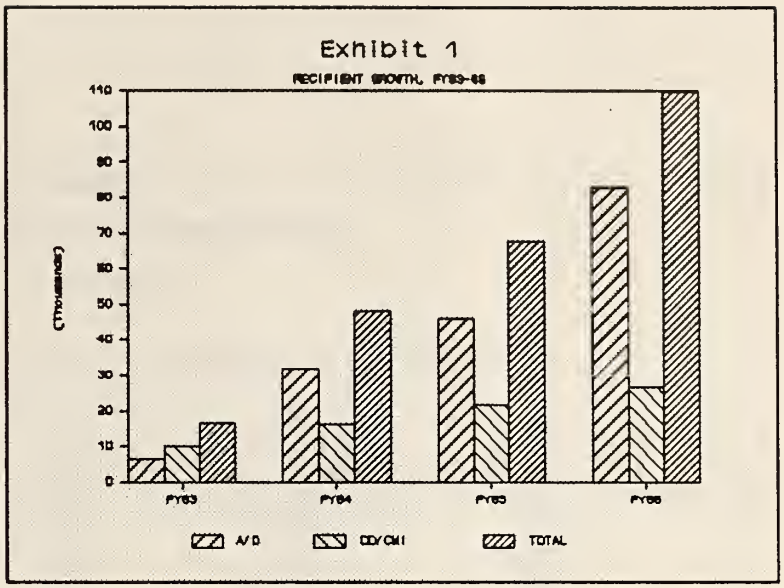
[1] Clinkscale, R. and Ray, S. SURVEY OF MEDICAID HOME AND COMMUNITY-BASED CARE WAIVERS: FISCAL YEAR 1986, Medicaid Program Evaluation Paper No. 1.11, Health Care Financing Administration, U.S. Department of Health and Human Services, December, 1987.

The DD/CMI recipient is more costly to serve because funds for residential care staff and day habilitative training programs cover cost 24 hours a day 7 days a week. In contrast, A/D services such as homemaker or personal care and adult day care are relatively inexpensive and involve only four or five hours a day for less than five days per week. A/D waiver services only augment those provided by family and friends. Without substantial informal care already in place, the A/D waiver services alone would not be sufficient to enable the typical nursing home level of care frail elderly person to live independently.



2. WAIVERS FOR THE AGED AND DISABLED

About three-quarters of the A/D waiver population is represented by frail elderly persons usually having multiple chronic impairments or disabilities. The effect of chronic illness has rendered them functionally impaired so that they need help with the performance of simple activities of daily living such as eating, toileting, bathing, moving about, and dressing. Some suffer from mental disabilities as well. The disabled population may not be aged but have common problems due to one or more chronic disabling conditions.

(a) Number and Size of Waiver Programs

In FY86 there were 43 active A/D waivers, although only 36 were active throughout the entire FY 86. The 7 waivers excluded from the analysis were insignificant in terms of size. Exhibit 2 on the following page presents a profile on each of the 36 A/D waivers in terms of enrollment levels (1986 unduplicated waiver recipients), total A/D Medicaid recipient caseload during FY86 (1986 unduplicated A/D recipients), and the overall penetration rate. The penetration rate measures the waiver recipient count divided by the total count of A/D institutionalized Medicaid recipients plus waiver recipients in the State for the given fiscal year.

There were an estimated 82,981 A/D waiver recipients in FY86. The average size of a waiver was 2,305 individuals. However, the average has little meaning when the variance among States is so great. Almost half the total number of waiver recipients were enrolled in five programs (IL 0015, FL 0010.90, OR 0113, CA 0004 and GA 0112.90). The A/D waivers in FY86 varied greatly in size among States. Some States served less than a few hundred recipients while a few others served over 5,000.

Although the 36 waivers served an estimated 82,981 recipients, there was over 1 million total Medicaid recipients in nursing homes. This means that only 7.3 percent or only one out of every 14 Medicaid long-term care A/D recipients are living in a home or community setting relative to the total population at-risk. Penetration rates vary greatly among State waiver programs. For example, AL 0068, CO 0006.90, FL 0010.90, OR 0113, and SC 0104 are close to 15 percent and above. Many waivers reported rates well below 5 percent. The large waiver programs having 5,000 or more annual recipients, also tend to have relatively high penetration

EXHIBIT 2

A/D WAIVER PROGRAM PENETRATION RATES

N = 36 Waivers

STATE/WAIVER#	1986 UNDUPLICATED WAIVER RECIPIENTS a/	1986 UNDUPLICATED A/D RECIPIENTS b/	PENETRATION RATE
AL 0068	3,624	20,992	14.7%
CA 0004	6,335 c/	129,420	4.7%
CA 0005	131	-	0.1%
CO 0006.90	3,300	14,261	18.8%
CT 0138	723	26,477	2.7%
FL 0010.90	7,506	45,487	14.2%
FL 0116	570	45,487	1.2%
GA 0112.90	5,322	37,203	12.5%
HI 0057	199	4,089	4.6%
HI 0114	45	-	1.1%
ID 0076	329	4,864	6.3%
IL 0015	12,483	81,097	13.3%
IN 0066	39	43,436	0.1%
KS 0018.90	1,978 c/	14,791	11.8%
KY 0020	358	22,054	1.6%
LA 0121	305	31,508	1.0%
MA 0059	1,900	46,267	3.9%
ME 0088	1,080	9,379	10.3%
MN 0025	1,662	42,914	3.7%
MO 0026.90	4,121	29,872	12.1%
MO 0065	29	-	0.1%
MT 0029	306	5,006	5.8%
NC 0132	1,171	27,644	4.1%
ND 0054	188 c/	6,659	2.7%
NH 0060	157	5,624	2.7%
NJ 0032	2,197	34,548	6.0%
NM 0033	419 c/	4,870	7.9%
NY 0340	4,453	111,481	3.8%
OH 0067	559	69,216	0.8%
OR 0113	9,674 c/	11,650	45.4%
RI 0040	437 c/	10,990	3.8%
SC 0104	5,266	12,730	29.3%
VA 0048.90	2,996	20,745	12.6%
WA 0049	2,737	23,469	10.4%
WI 0111	183	57,912	0.3%
WV 0134	199	7,944	2.4%
Total:	82,981	1,060,086	
Average:	2,305		
Overall Penetration Rate:			7.3%

a/ La Jolla 1986 Waiver Survey.
b/ HCFA FY86 Annual Form 2082 data.
c/ Data obtained from HCFA 372 information.
- Represents the same number of unduplicated recipients as related in the line immediately above.

rates. Illinois is both the largest A/D waiver program and one of the highest in terms of penetration rates. Oregon has almost as many people in their waiver program as they have in nursing homes.

Although national penetration rates for the A/D waivers is still relatively small in relation to all Medicaid recipients in nursing homes, the 7.3 percent rate in FY86 is significantly higher that the FY85 estimate of 4 percent. Using the penetration rate as a measure of growth the waiver program is increasing rapidly.

(b) Targeting to the At-Risk Population

States may use a variety of screening mechanisms to restrict or target waiver entry only to those individuals who would, but for the waiver services, occupy a nursing home bed. A targeting accuracy of 100 percent would mean that there is no one in the waiver program that would not otherwise be in a nursing home. Anything less than 100 percent means for some recipients the waiver services are an "add on" in the sense that they would not really occupy a nursing home bed if the waiver service was denied or withheld. For these recipients, there are no nursing home expenditure reductions to offset the cost of the waiver services. If this happened frequently enough the waiver program would be a net cost to Medicaid.

States influence targeting accuracy in their degree of scrutiny of waiver applicants. Some States restrict waiver entry only to those individuals already in institutional care (deinstitutionalization) while others have elaborate preadmission screening mechanisms to redirect (deflect) nursing home bound individuals to remain in their homes by offering an appropriate package of home care services that enable the individual to remain at home or in the community. Our annual survey asked States to identify screening devices used other than the Federal regulations that require recipients to be Medicaid eligible and certifiable for acute or nursing home levels of care.

Only a few A/D waivers limit entry to institutionalized individuals. Approximately three-quarters of all A/D waiver recipients enter the waiver from home rather than an institutional setting. Less than 10 percent of individuals enter a waiver through a hospital or nursing home setting. The prevailing view is that once people are institutionalized for an indefinite period of time it is difficult to restructure their lives back into the community. Waiver services are better targeted to those still at home or in the community who are at high risk of entering a nursing home. States such as Virginia, South Carolina and Minnesota follow this practice but only because they integrate waiver entry with very stringent mandatory nursing home preadmission screening (PAS) programs.

Other States waivers (AL 0068, CA 0004, FL 0010.90, IL 0015, KY 0020, KS 0018.90, and LA 0121) report that they will accept applicants who are already living at home or in the community without their having to apply for nursing home entry based only on the applicant being considered at high risk of eventual nursing home entry. This criterion alone may not be a very effective screen against individuals being admitted to the waiver who are not, in reality, nursing home bound.

(c) Recipient Characteristics

Factors such as age, sex, marital status, functional impairments, and general health are significant indicators of the need for long-term care. In general, a population cohort is considered at the highest risk of nursing home entry if they are 85 years of age or above, poor, female, single living alone, and without children close by to provide support. Note that while these risk criteria may hold for a large group of individuals, they may not be valid for a single individual. The presence of medical and mental problems add significantly to the

risk.[2] The findings given below examine the waiver population with this profile in mind. Our overall finding is that the A/D waiver population looks fairly similar to their cohorts in nursing homes in terms of the above risk criteria. The waiver population is slightly younger, slightly less functionally impaired, very similar in terms of medical conditions and less mentally impaired than nursing home residents.

1. Age, Sex and Marital Status

About one-quarter of the total A/D waiver population is young (0-64 years of age), but disabled. Another quarter are in the "young old" age bracket (65-74 years of age). Of the remaining half, 30 percent were in the 75-84 age bracket while only 20 percent were 85+ years of age. This latter age bracket is considered the one in which there is the greatest need for nursing home care. Overall, the age of the waiver population is younger than the typical nursing home population.[3] On the one hand, this finding could mean that younger less-at-risk age groups are finding their way into the waivers. On the other, it could mean that the waiver programs are reaching population groups who are at high risk of nursing home entry at younger ages due to poverty and lack of family support.

The A/D waiver population is predominately female, and about three-quarters have no spouses. Only 22 percent are married. State data on the strength of informal support available to A/D recipients is generally not available for research or reporting purposes. Without these data, a complete at-risk profile of A/D recipients cannot be accomplished.

2. Health and Functional Status

States were asked to classify their A/D waiver recipients in terms of four functional dependency categories. The four functional categories represent a continuum of dependency severity based on the well-known activities of daily living (ADL) scale. The survey findings indicated that about 15 percent of the A/D clients had either no ADL deficiency or simply needed help with mobility. The great majority had functional deficiencies in toileting and eating (45 percent) or bathing and dressing (39 percent). This finding supports the fact that A/D waiver recipients are as physically impaired as their cohorts in nursing homes (NCHS, 1977 National Nursing Home Survey).

Survey respondents were also asked to report known client medical conditions. Although most States do not have the data systems to gather these data, six of the A/D waivers did based on a total of about 12,000 clients. Circulatory disorders (36 percent) was the most prevalent diagnostic condition, followed by cancers (19 percent), musculoskeletal disorders (12 percent) and respiratory disorders (10 percent). Only 6 percent of A/D waiver clients were reported to

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[2] Macken, C. "A Profile of Functionally Impaired Elderly Persons Living in the Community," HEALTH CARE FINANCING REVIEW, 7(4), Summer, 1986; and Weissert, W. and Scanlon, W. DETERMINANTS OF INSTITUTIONALIZATION OF THE AGED, The Urban Institute, Washington, D.C., 1983; and Cohen, M. et al, "Client-Related Risk Factors of Nursing Home Entry Among Elderly Adults," JOURNAL OF GERONTOLOGY, 41(6), 1986.

[3] According to the 1977 National Nursing Home Survey, 35 percent of nursing home residents were age 85 or older; National Center for Health Statistics, U.S. Department of Health and Human Services.

suffer from mental disorders. The latter is a particularly important indicator of at-riskness of institutional care. According to the 1977 National Nursing Home Survey, 20 percent of patients suffered from some form of mental disorders. This figure is probably higher today given the emerging prevalence of Alzheimer's disease. The above finding regarding the general medical condition of A/D waiver clients suggests that they are similar to their cohorts in nursing homes with respect to general medical conditions; however, they are considerably less mentally impaired than nursing home residents.

In summary, A/D waiver recipients are somewhat younger than their cohorts in nursing homes, are similar in terms of physical impairments, are similar in terms of overall medical conditions, and are far less mentally impaired than their nursing home cohorts. This finding is to be expected since nursing home statistics are weighted by very old residents in very poor health who would not be candidates for a waiver program under any conditions.

(d) Service Utilization

Case management, personal care and homemaker services are the backbone of the A/D waiver programs. These services are provided, by far, more often than any of the others. About 63 percent of all A/D clients receive case management services. The actual figure is likely to be even higher since some States fund case management as a regular Medicaid service and not as a waiver service. Case management services do not technically include screening and assessment, but do include developing a plan of care, arranging for client services, monitoring client progress, and generally following up to make sure that the client's needs are being met. Often, this is the only service needed, especially when there are adequate sources of support already available in the community. The client's problem was not knowing how or where to go for help.

Personal care and homemaker services are designed to provide a wide variety of "home help" to frail elderly and disabled recipients including very important activities such as: cleaning, shopping/errands, meal planning, bathing, grooming, dressing, medication monitoring, toileting, transferring, ambulation, eating/feeding, yard work and minor home repair, financial management, and companion services. Although fine distinctions are often made to distinguish personal care services from homemaker services, the two service types are generally the same. A definition (scope of activities) for personal care services in one waiver may often be the same for homemaker services in another waiver. Each waiver defines each service somewhat differently, although the differences are minor.

Usage of home health aide and adult day health services were reported to be very low, about 6 percent of recipients. This is probably because home health aide is more medically oriented than personal care/homemaker services and fewer clients need such services. Adult day health (out-of-home social/recreational services, RN monitoring and supervision, therapies, meals, etc.) is more appropriate for the less impaired elderly and disabled and is rarely seen as a substitute for nursing home care. Respite care is, by definition, used infrequently. Examples of other services include skilled nursing, various types of therapies, transportation, durable medical equipment and other special adaptive equipment for the home.

(e) Expenditures

An estimated $165,000,000 was spent on A/D waiver services during FY86, up considerably from $96 million in FY85. The average expenditure per recipient was $2,092; a little over the FY85 estimate of $2,008. The average size of an A/D waiver in terms of expenditures was $4,568,000. Of the total $165 million expended, approximately 60 percent was spent on personal care or homemaker services. Among 20 waivers responding to our FY86 waiver survey, the average cost per day for waiver services was $16 whereas the same cost for

a day in a nursing home was closer to $40 per day. These estimates demonstrate the potential for waiver budget neutrality or even savings to Medicaid. Whether this potential is being realized is a complicated issue.

Exhibit 3 presents estimated spending by each of the 36 A/D waivers active throughout FY86. The range of both total and per recipient expenditures varies greatly across waivers. The reason for very high expenditure levels per recipient for the CA 0005 and MO 0065 is the fact that these are former model waivers exclusively serving severely disabled recipients such as ventilator patients who require at least an 8 hour shift of skilled nursing care every day in order to be maintained at home instead of a hospital.

The great variance in expenditures per recipient no doubt reflects local choices given local nursing home per diem rates, judgments as to which waiver services best met the needs of their target population and the local unit cost of waiver services. Since most States elected to cover either personal care or homemaker services, additional choices as to whether to include case management and adult day care are the biggest factors that explain cost per recipient variations among States.

3. WAIVERS FOR THE DEVELOPMENTALLY DISABLED/CHRONICALLY MENTALLY ILL

Only one-quarter of all waiver recipients are individuals with developmental disabilities or chronic mental illness. Most are mentally retarded. Mental retardation is generally defined in terms of significantly below average intelligence quotient and significantly limited ability to adapt in age-appropriate ways to the surrounding environment. The Developmental Disabilities Act of 1984 refers to severe, chronic, physical or mental disability that occurs prior to young adulthood and that results in substantial limitations in at least three of the following major life activities: self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.[4]

Medicaid eligibility is tied to having substantial functional limitations in at least three of the above major life activities, with the exception of the capacity for economic self-sufficiency. Medicaid stipulates that federal support be available both to mentally retarded individuals and to persons with "related conditions" such as cerebral palsy, severe and uncontrolled epilepsy, autism, and other neurological and sensory impairments. While the more general definition of developmental disability could include some forms of mental illness, mental illness is usually considered a separate condition.

(a) Number and Size of Waiver Programs

One-quarter or 26,647 of the 109,628 FY86 waiver program recipients nationwide were served through 40 DD/CMI waivers. Most were mentally retarded. Seven States also provided waiver services to other developmentally disabled recipients, including those suffering from cerebral palsy, epilepsy, autism and other developmentally disabling conditions. Three States - Oregon, Rhode Island and Vermont administered waiver programs for the chronically mentally ill. Exhibit 4 presents data on 38 of 40 DD/CMI waivers (the missing two were very small and not operational throughout FY1986).

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[4] U.S. Department of Health and Human Services, REPORT TO THE SECRETARY: WORKING GROUP ON POLICIES AFFECTING MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS, Chairman, Robert B. Helms, Assistant Secretary for Planning and Evaluation, March 1988.

EXHIBIT 3

A/D WAIVER RECIPIENT COUNTS AND EXPENDITURES,
RANKED BY EXPENDITURES a/
N = 36 Waivers

ST/WAIVER	ACTIVE CASELOAD 1986	UNDUPLICATED RECIPIENTS 10/1/85 - 9/30/86	TOTAL EXPENDITURES FY86	COST PER RECIPIENT	CUM PERCENT TOTAL EXP
IL 0015	8,500	12,483	$24,351,792	$1,951	14.81%
OR 0113	5,160 b/	9,674 b/	$17,562,604 b/	$1,815	25.49%
WA 0049	2,150	2,737 c/	$13,089,348	$4,782	33.45%
VA 0048.90	2,200	2,996	$10,560,328	$3,525	39.87%
AL 0068	3,624	3,624	$9,609,851	$2,652	45.72%
GA 0112.90	4,477	5,322	$9,096,391	$1,709	51.25%
NJ 0032	1,658	2,197	$8,544,333	$3,889	56.44%
CO 0006.90	2,500	3,300	$8,353,500	$2,531	61.52%
CA 0004	4,515	6,335	$8,072,673	$1,274	66.43%
CA 0005	111	131	$7,854,542	$59,958	71.21%
SC 0104	2,629	5,266	$6,216,411	$1,180	74.99%
FL 0010.90	7,506	7,506	$5,315,512	$708	78.22%
NC 0132	1,007	1,171	$4,463,190	$3,811	80.94%
MA 0059	1,400	1,900	$4,000,000	$2,105	83.37%
MN 0025	1,200	1,662	$3,621,222	$2,179	85.57%
MO 0026.90	3,425	4,121	$2,362,140	$573	87.01%
FL 0116	427	570	$2,342,109	$4,109	88.43%
KS 0018.90	580 b/	1,978 b/	$2,052,083 b/	$1,037	89.68%
NM 0033	419 c/	419 c/	$2,018,839 c/	$4,818	90.91%
NY 0034	3,209	4,453	$1,915,929	$430	92.07%
OH 0067	321	559	$1,582,859	$2,832	93.03%
HI 0057	150	199	$1,421,204	$7,142	93.90%
MT 0029	336 b/	306 b/	$1,322,434 b/	$4,322	94.70%
WI 0111	151	183	$1,146,218	$6,263	95.40%
WV 0134	158	199	$1,036,297	$5,208	96.03%
CT 0138	250	723	$998,331	$1,381	96.64%
ID 0076	226 b/	329 b/	$998,302 b/	$3,034	97.24%
RI 0040.90	437 c/	437 c/	$951,900 c/	$2,178	97.82%
ME 0088	551	1,080	$831,878	$770	98.33%
LA 0121	260	305	$788,010	$2,584	98.81%
MO 0065	23	29	$620,355	$21,392	99.19%
KY 0020	281	358	$493,696	$1,379	99.49%
ND 0054	188 c/	188 c/	$342,407 c/	$1,821	99.69%
HI 0014	26	45	$242,818	$5,396	99.84%
NH 0060	157	157	$242,072	$1,542	99.99%
IN 0066	32	39	$17,474	$448	100.00%
TOTALS:	60,244	82,981	$164,439,052	$1,982	100.00%

a/ The following 7 active waivers were excluded from the survey because they were not active throughout FY 86: DE 0136, FL 0118, KY 0055, ME 0126, MA 0024, TN 0062, and TX 0045. There were 43 active A/D waivers in all.

b/ These are combination waivers. Oregon 0113 is a combination waiver serving both AD and DD/CMI groups. This represents a best estimate of the A/D component. Data are for the Jan-Dec 1986 time period.

c/ Data obtained or inferred from the latest approved HCFA Form 372 reports submitted annually by the States. Some States reported for a slightly different time period.

Source: La Jolla 1986 Waiver Survey and HCFA Form 372 Data.

EXHIBIT 4

DD WAIVER PROGRAM PENETRATION RATES

N = 38 Waivers

STATE/WAIVER #	1986 UNDUPLICATED WAIVER RECIPIENTS a/	1986 UNDUPLICATED ICF-MR RECIPIENTS b/	PENETRATION RATE
AL 0001.90	1,592	1,431	52.7%
CA 0129	3,115	9,960	23.8%
CO 0007.91	1,435	1,574 d/	47.7%
DE 0009	80 c/	438	15.4%
FL 0010.91	7,506	3,439	68.6%
HI 0113.90	46	240	16.1%
ID 0076	138	512	21.2%
IL 0016	585 c/	9,768	5.7%
KS 0018.90	585	1,737	25.2%
KY 0019.91	567	1,266	30.9%
MA 0064	520	3,501	12.9%
MD 0023	604	1,810	25.0%
ME 0022	383	714	34.9%
MN 0061	817 c/	8,035	9.2%
MT 0029	201	265	43.1%
NC 0036	321	3,160	9.2%
ND 0037	608 c/	719	45.8%
NH 0053	503	300	62.6%
NJ 0031.90	2,058	4,031	33.8%
NM 0056	85	643	11.7%
NV 0125	135	218	38.2%
OK 0094	146 c/	3,178	4.4%
OR 0113	895 c/	1,727	34.1%
OR 0117	583 c/	-	19.4%
PA 0039	244	7,943	3.0%
PA 0058	160	-	2.0%
PA 0096	45	-	0.6%
PA 0099	54	-	0.7%
PA 0135	40	-	0.5%
RI 0041	339 c/	1,157	22.7%
RI 0042	232 c/	-	16.7%
SD 0044.90	589	743	44.2%
TX 0110.01	68	13,546	0.5%
VT 0047.90	188	248	43.1%
VT 0047.91	75	-	23.2%
WA 0050.01	930	2,769	25.1%
WI 0052	120	2,296	5.0%
WV 0133	55	254	17.8%
Total:	26,647	87,622	
Average:	701		
Overall Penetration Rate:			23.3%

a/ La Jolla 1986 Waiver Survey.
b/ HCFA FY86 Annual Form 2082 data.
c/ Data obtained from approved HCFA 372 Form.
d/ FY86 HCFA Annual Form 2082 data not reported, FY85 used.
- = Represents the same number of unduplicated recipients as related in the line immediately above.

There were an estimated 26,647 DD/CMI waiver recipients in FY86. The average size of a waiver was 701 individuals. However, the average has little meaning when the variance among States is so great. Over half of all DD/CMI of waiver recipients were enrolled in five programs (FL 0010.91, CA 0129, NJ 0031.90, AL 0001.90, CO 0129). The DD/CMI waivers in FY86 varied greatly in size among States. Some States served less than a few hundred recipients while a few others served thousands.

Although the 38 waivers served an estimated 26,647 recipients, there were approximately 87,662 Medicaid recipients of ICF-MRs. This means that the overall penetration rate for the DD/CMI waivers was about 23.3 percent. The penetration rates vary greatly among State waiver programs. For example, AL 0001, CO 0007.91, FL 0010.91, and NH 0053 were close to or over 50 percent. Over ten waivers had penetration rates below 10 percent. The larger waivers also tended to have high penetration rates. Florida is both the largest DD/CMI waiver program (7,506 recipients) and has the highest penetration rate (68.6). This means that in Florida there are now more DD/CMI recipients of the waiver program than are still residing in ICF-MRs.

(b) Targeting to the At-Risk Population

A primary issue in targeting DD/CMI waiver services for the developmentally disabled is whether a waiver is used primarily to deinstitutionalize clients from ICF-MR certified facilities, or whether it is used to divert clients already living in the community from institutional placement. Of the 28 programs that responded to the FY86 survey, seven programs limited eligibility to the residents of ICF-MRs or other State institutions. In the remaining 21 DD waivers, persons in the community, but at-risk of placement in an ICF-MR, were also eligible for waiver services.

Since ICF-MR level of care criteria are the primary screening mechanisms employed to determine eligibility for waiver services, the survey asked States to briefly describe the applicable ICF-MR level of care criteria in their respective States. Federal Medicaid regulations on ICF-MR level of care criteria are fairly non-restrictive. Medicaid regulations (42 CFR 440.150 and 442.418) only require that ICF-MR recipients:

- Have a diagnosis of mental retardation or other developmental disability,
- Require services above the level of room and board, and
- Be in need of active treatment.

More restrictive criteria for ICF-MR placement may be established at the discretion of the State. Frequently, such criteria also apply to the waiver program. In those States that go beyond the Federal criteria, examples of the more restrictive ICF-MR level of care criteria include: documented deficits in two or more behavioral or self-care skill domains, the need for more intensive treatment than can be provided in a day treatment program or the need for 24 hour supervision, habilitation and active treatment. Some States required that intelligence quotient (IQ) levels be utilized in determining ICF-MR level of care criteria; potential clients with IQ levels above the established level were not allowed program admission unless severe deficits in adaptive behavior were be demonstrated. A few States followed lengthy and complex entrance criteria.

The most common entry point among recipients who entered the program in FY86 was from a noninstitutional setting, i.e., a group home or private residence. Approximately 32 percent entered from group residences and 21 percent entered from private residences. About 6 percent of the recipients entered from unknown (untraced) sources. Forty-one percent of all waiver clients entered the program from an ICF-MR or other institutional facility, such as a nursing home or hospital. These data would suggest that the States are putting a balanced

emphasis on admitting clients to the waiver from both ICF-MRs and from existing community settings. There is no way of knowing whether the waiver entrants from either setting would remain in or go to ICF-MRs or other State institutions if the waiver services were not available.

(c) Recipient Characteristics

The majority of DD waiver clients (55 percent) are young adults, aged 22-39. Fifty-six percent of all DD waiver clients are male, which is reflective of the overall mentally retarded population. In comparison to the ICF-MR population in waiver States, waiver recipients are about the same age. For example, 75 percent of waiver recipients were under the age of 40, compared to 72 percent of the ICF-MR population.

Waiver recipients differ significantly, in terms of level of retardation, from the ICF-MR population in waiver States, as surveyed in 1982.[5] Within the ICF-MR population, mildly and moderately retarded individuals accounted for 22 percent, compared to 51 percent of the waiver population. By only two percentage points, severely retarded individuals comprised a somewhat higher proportion of waiver recipients (28 percent) than ICF-MR recipients (26 percent). In 1982, profoundly retarded individuals made up 53 percent of the ICF-MR population compared to 20 percent of the waiver population in 1986. This distribution of waiver recipients by level of retardation more closely resembles the characteristics of mentally retarded individuals in residential facilities which were not certified as ICF-MRs in 1982 than they resemble the characteristics of ICF-MR recipients.

Waiver recipients and ICF-MR recipients can be compared within four functional activities of daily living (ADL): toileting, ambulation, dressing and verbal communication. On these criteria, waiver recipients were significantly less impaired than ICF-MR recipients. The prevalence of deficits in each functional area is generally five times higher in the ICF-MR population than in the waiver population.

These data suggest that, on average, the waiver population is not as impaired as the ICF-MR population, however this does not necessarily mean that waiver programs are not substituting for ICF-MR care. The waiver's main objective is to serve clients who are at-risk of institutionalization, as long as they can be served equally well in non-institutional settings. Of the total population in ICF-MRs or at-risk of ICF-MR placement, one would expect the waiver to focus on the relatively higher-functioning clients for whom ICF-MR care is not the most appropriate care setting. In a positive sense, our findings indicate the considerable overlap between the waiver population and the ICF-MR population, as well as the fact that almost half of all waiver clients are either severely or profoundly retarded.

(d) Service Utilization

The most frequently utilized services are residential care, habilitative services, case management, transportation, prevocational training and "other services" such as home mobility aids, specialized foster care, crisis intervention, family placement and in-home training.

1. Residential Services

   Nearly one-half (49 percent) of all DD/CMI waiver clients reside in group homes. Usually, these are staffed single-family dwellings which house between three and 12 clients. Staff either live in or rotate shifts. For at least part of the

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[5] Lakin, K., Hill B. and Bruininks, R. (eds.) AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FOR THE MENTALLY RETARDED (ICF-MR) PROGRAM, University of Minnesota, 1985.

day during the regular workweek, clients participate in a developmental training program, sheltered workshop or transitional employment program, depending on individual skill levels. The actual cost of room and board is not an allowable waiver service, although the cost of residential program staff is often covered under the waiver. Typically, the clients' SSI/SSP income and general State funds pick up the costs of room and board. Within these group homes, staff requirements are generally not as intensive as in small scale ICF-MRs, nor are life and safety codes as stringent as ICF-MR standards.

Another third of waiver clients reside with their parents in private homes. In such cases, the waiver pays for day programs, transportation services, respite care and other services; residential services are not covered. Under the optional waiver of deeming regulations, States can extend Medicaid eligibility to individuals residing at home with their parents who, due to the deeming of parental income under usual Medicaid eligibility rules, would otherwise not be eligible for medical assistance. It is important to note that the proportion of waiver clients living at home with parents is significantly higher than the percentage of clients which States reported have been made eligible for Medicaid under this special provision, thus suggesting that most waiver clients living at home are in Medicaid-eligible households.

A relatively small percentage of clients lived in either foster homes (4 percent), supervised apartment programs (8 percent) or in other private residences (3 percent).

2. Habilitation Services

Habilitation services represent a broad array of services designed to help the individual achieve maximum independence. Services may be provided by the facility or through contracts with other providers. Every resident must have a written plan of care and be receiving "active treatment." Habilitation programs are often aimed at improving the functional levels of individuals to give them the ability to live both more independently and more productively within the community.

Waiver residents typically attend these "day programs" during the workweek. The resident is typically picked up in a van by a contractor and transported to the site of the habilitation program. After the days activity, the resident is transported back to their residential care home. Many of the programs now offer prevocational employment programs as the front end to vocational education training and employment programs. In the best programs, actual services are individually tailored to appropriately meet the level and needs of the clients.

3. Case Management

Virtually all DD/CMI waiver recipients receive case management services. Case management is increasingly viewed as a critical component in the developmental disabilities service system. The case managers key function is to ensure the coordination of services in meeting the individual client's program goals. It is not unusual for a person to have two or more service plans. For example, children receiving special education services have an Individualized Education Plan (IEP) while those individuals living in an ICF-MR or waiver must have an Individualized Program Plan (IPP). When a person becomes eligible for vocational rehabilitation services an Individualized Written Rehabilitation Plan (IWRP) is developed. Ideally these service plans should be

coordinated to ensure continuity and complementary activities. The case management function works differently with different waiver programs. Sometimes the case manager is an independent contractor "independent" from both Medicaid and the community care providers. Sometimes the case management function is retained by a public agency. Placement of the function depends on the unique needs and situation in each State.

The value of residential living and habilitation services to disabled individuals is extremely high. There is considerable research evidence that advances in adaptive behavior and independent living are associated with: (a) community living arrangements in small family-like settings and (b) learning experiences which provide opportunities for interaction with non-disabled people.[6]

(e) Expenditures

An estimated $221 million was spent on DD/CMI waiver services during FY86, up considerably from $161 million in FY85. The average expenditure per recipient was $8,281; considerably over the FY85 estimate of $7,259. The average size of a DD/CMI waiver in terms of expenditures was $5.8 million. Of the total $221 million expended, approximately half was spent on residential services, 25 percent on habilitation services, and 25 percent on case management and "other services." The average FY86 cost per waiver day was reported by 28 States to be approximately $68 as compared to ICF-MR per day costs of $108. This wide difference in the averages reinforces the potential for DD/CMI waivers to be at least budget neutral. Waiver program budget neutrality "break-even points" are unique to each waiver.

Exhibit 5 presents estimated spending by each of the 38 DD/CMI waivers active throughout FY86. The range of both total and per recipient expenditures varies greatly across waivers. The reason for such variances are many but primarily relate to differences in the costs for residential care services, i.e., group home staffing costs per client. This cost can vary due to significant differences among State policies regarding living unit size and staffing requirements, as well as local labor costs.

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[6] Conroy, J. and Bradley, V. THE PENNHURST LONGITUDINAL STUDY: A REPORT OF FIVE YEARS OF RESEARCH AND ANALYSIS, Developmental Disabilities Center, Temple University, 1985.

EXHIBIT 5

DD WAIVER RECIPIENT COUNTS AND EXPENDITURES,
RANKED ORDERED BY EXPENDITURES /a

N = 38 Waivers

ST/WAIVER	ACTIVE CASELOAD 1986	UNDUPLICATED RECIPIENTS 10/1/85 - 9/30/86	TOTAL EXPENDITURES FY86	COST PER RECIPIENT	CUM PERCENT TOTAL EXP
CA 0129	2,432	3,115	$26,215,375	$8,416	11.88%
NJ 0031.90	1,993	2,058	$22,893,275	$11,124	22.25%
CO 0007.91	1,300	1,435	$22,700,283	$15,819	32.54%
MD 0023	581	604	$16,743,168	$27,720	40.13%
FL 0010.91	2,571	7,506	$16,705,100	$2,226	47.70%
MA 0064	520	520	$11,102,253	$21,350	52.73%
NH 0053	486	503	$10,706,228	$21,285	57.58%
PA 0039	257	244 b/	$9,725,130	$39,857	61.99%
KY 0019.91	546	567	$9,670,896	$17,056	66.37%
WA 0050.01	877	930	$8,016,485 c/	$8,620	70.00%
AL 0001.90	1,592	1,592	$7,831,197	$4,919	73.55%
IL 0016	585 c/	585 c/	$7,187,283 c/	$12,286	76.81%
MN 0061	530	817 c/	$5,939,033	$7,269	79.50%
SD 0044.90	498	589	$5,075,497	$8,617	81.80%
PA 0058	160	160	$4,711,426	$29,446	83.94%
VT 0047.90	188	188	$4,368,000	$23,234	85.92%
ME 0022	375	383	$4,037,620	$10,542	87.75%
ND 0037	608 c/	608 c/	$3,795,931 c/	$6,243	89.47%
MT 0029	191	201	$3,426,684	$17,048	91.02%
OR 0117	583	583	$3,409,917 c/	$5,849	92.56%
NC 0036	331	321	$2,311,268	$7,200	93.61%
OR 0113	895 d/	895 d/	$1,995,608 d/	$2,230	94.52%
KS 0018.90	419	585	$1,680,514	$2,873	95.28%
WI 0052	120	120	$1,653,157	$13,776	96.03%
NV 0125	111	135	$1,413,467	$10,470	96.67%
VT 0047.91	44	75	$1,166,590	$15,555	97.20%
RI 0041	339 c/	339 c/	$1,090,092 c/	$3,216	97.69%
RI 0042	232 c/	232 c/	$920,344 c/	$3,967	98.11%
DE 0009	80 c/	80 c/	$559,502 c/	$6,994	98.36%
NM 0056	85 c/	85 c/	$545,121 c/	$6,413	98.61%
TX 0110.01	71	68 e/	$542,034	$7,971	98.85%
PA 0099	61	54 b/	$511,173	$9,466	99.09%
WV 0133	55	55	$502,000	$9,127	99.31%
ID 0076	127	138	$418,740	$3,034	99.50%
HI 0113.90	48	46	$410,542	$8,925	99.69%
PA 0096	53	45 b/	$360,864	$8,019	99.85%
OK 0094	94	146 c/	$180,985	$1,240	99.93%
PA 0135	47	40 b/	$144,816	$3,620	100.00%
TOTAL	20,085	26,647	$220,667,598	$8,281	100.00%

a/ The following active waivers were excluded from the survey because they were not active throughout FY 86: PA 0147 and TN 0128, both were not implemented until July, 1986.
b/ Data reported for July 1985 - June 1986.
c/ Data obtained or inferred from the latest approved HCFA Form 372 reports submitted annually by states.
d/ Oregon 0113 is a combination waiver serving both A/D and DD/CMI groups. This represents a best estimate of the DD/CMI component. Data are for the Jan-Dec 1986 time period.
e/ Data reported for September 1985 - August 1986.

Source: La Jolla 1986 Waiver Survey and HCFA Form 372 Data.

CHAPTER THREE
FINDINGS FROM SPECIAL STUDIES

In addition to the survey findings described in the previous chapter, we undertook two special studies using national data and six separate State waiver case studies. This chapter presents a summary of our findings from each of these special studies.

1. FINDINGS FROM NATIONAL LEVEL STUDIES

Two special studies were undertaken using data available at the national level on all State Medicaid programs. The first is a study of the annual State reports to HCFA regarding their waiver programs. The second study is an statistical analysis of the extent to which nursing home and ICF-MR use and expenditures trends were affected in States opting to implement waivers.

(a) Waiver Impacts Based on State Annual Reports to HCFA[1]

HCFA requires States granted waivers to annually report data on recipients and expenditures, both for waiver recipients and for their counterparts in nursing homes and ICF-MRs. The purpose of the reports is to allow HCFA to track the extent to which the waiver programs are cost-effective (budget neutral to Medicaid). The reporting form is the HCFA 372. Our analysis was done in 1986 using available approved HCFA 372 forms from States.

Analysis of data from State reports to HCFA (HCFA Form 372) indicate that Medicaid expenditures are lower for waivered clients as compared to persons in institutions. Among the reporting States, the average annual total Medicaid expenditure per full person-year of A/D waiver coverage was $8,273 as compared to $12,435 for a year in a nursing home setting. This represents a potential savings of $4,162 per year of coverage; or a one-third reduction.

Data reported for the MR/DD group show greater potential for cost savings; e.g., $11,027 per year for waivered recipients compared to $25,453 per year for ICF-MR residents; a reduction of almost 60 percent per person-year of coverage. Unfortunately, these data were available on only a small number of waivers (eight second year waiver reports approved by HCFA) and may not be completely representative. They do, however, support the notion that home and community care can be considerably less expensive for Medicaid than institutional care.

The potential for cost saving based upon this 1986 analysis of approved HCFA 372s is based on an assumption that all those receiving waiver care otherwise would use nursing homes or an ICF-MR. Most evaluation research studies, including this one, do not support the notion that States generally target home care services only to those otherwise residing in institutional care. At best, their ability to discriminate between nursing home bound individuals and those who would use the

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[1] Based on the analysis reported in Clinkscale, R. and Vertrees, J. EVALUATION OF MEDICAID SECTION 2176 HOME AND COMMUNITY CARE WAIVERS, Interim Report, Medicaid Program Evaluation Working Paper No. 1.10, Health Care Financing Administration, December 1986.

services to augment their care in the community (woodwork effect) is 50 percent accurate.[2] For most States, the ratio of institutional to waiver costs is not high enough to compensate for a 50 percent error in targeting. That is, any savings from those correctly targeted would be more than wiped out by the costs of serving the other mistargeted 50 percent.

Unfortunately, this analysis is limited by the fact that the validity and reliability of the HCFA 372 data has recently been brought into question.[3] States reported to us that many had great difficulty with keeping accurate statistics on their waiver programs so as to satisfy HCFA reporting requirements. If the HCFA 372 data were reasonably accurate the potential of the waivers for reducing Medicaid expenditures is clear. This potential will not be realized for States not achieving targeting accuracy sufficient to offset waiver service costs with reduced nursing home expenditures.[4]

(b) Waiver Impacts on State Nursing Home Use and Expenditure Rates[5]

Several regression analyses were conducted in order to examine whether the waivers were as yet associated with any national trend reduction in nursing home use or expenditure rates. Separate analyses were conducted for A/D and MR/DD types of waivers using annual statistical data routinely reported by States to HCFA (HCFA Form 2082). The hypothesis was that the waivers had reduced the rate of growth in spending and recipients of institutional care. A comparison of these rates for each waiver and non-waiver State was conducted for the fiscal years 81-85, and a second analysis was done which updated the data to FY86.

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[2] See Blackman, D., et al. SOUTH CAROLINA COMMUNITY LONG TERM CARE PROJECT: REPORT OF FINDINGS, South Carolina State Health and Human Services Commission, 1985; Kemper, Peter, The Evaluation of the National Long Term Care Demonstration, HEALTH SERVICES RESEARCH: Health Services Research 23:1 (April 1988); and Kemper, P. and Applebaum, R., and Harrington M. "Community Care Demonstrations: What have we learned? HEALTH CARE FINANCING REVIEW 8(4):87-100, Summer 1987.

[3] General Accounting Office, DETERMINING COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED SERVICES, HRD-87-61, April 1987.

[4] Even if targeting accuracy were high (or even perfect) and the cost per day of waiver services were much less than the equivalent cost of institutional care, this does not guarantee waiver budget neutrality. The theory is that the cost of waiver services will be offset by reduced nursing home expenditures, and thereby render the waiver budget neutral to Medicaid (perhaps even save some money). It is normally assumed that relatively low waiver costs per day and high client targeting accuracy will guarantee the desired financial effect. This assumption will be false if nursing homes react to reduced demand from the waiver by filling otherwise empty beds with others backed up in hospitals or the community. The presence of waiting lists for nursing home beds can cancel out hoped for reduced nursing home expenditures. Another factor which can cancel out otherwise reduced institutional care costs is higher costs passed back to the consumer (Medicaid) due to lower occupancy and higher indirect cost rates. The issue of budget neutrality is therefore not nearly as simple as it seems.

[5] See Vertrees, J. and Clinkscale, R. WAIVER IMPACTS ON MEDICAID NURSING HOME USE AND EXPENDITURES, Medicaid Program Evaluation Working Paper No. 1.14, Health Care Financing Administration, August 1988.

For the aged and disabled programs we were concerned about the relatively small proportion of waiver recipients (up to 7.3 percent in FY86) in relation to total institutional care recipients. In addition, powerful changes were taking place at the same time, e.g., Medicare prospective hospital payments, nursing home bed supply regulations, etc. These factors would likely mask any waiver effects. The analyses indicated no statistical difference between nursing home use or expenditures in States implementing waivers and those that did not. Thus, no evidence was found to support the notion that the A/D waivers would reduce program spending rates. This result may well change as A/D waiver programs mature and grow in size.

The MR/DD waiver penetration rates were higher, up to about 23.3 percent by the end of FY86. However, like the A/D analysis, the small rate differences between waiver and non-waiver States was not statistically significant. The hypothesis that waiver services can reduce growth in ICF-MR use and outlays was not accepted.

2. SIX CASE STUDIES[6]

Six waivers were selected for intensive case study. The purpose of the case studies of individual waiver programs was to get a "closer look" at the waiver population, their at-riskness of institutionalization, appropriateness of waiver services relative to recipient needs, overall waiver cost-effectiveness, and quality assurance procedures. A brief summary of each of the six case studies is provided below.

(a) California Multipurpose Senior Services Program (MSSP)

The MSSP program serves an elderly, sick, and functionally impaired population of Medi-Cal recipients. Most of the MSSP recipients were elderly white females. Clients must be certifiable for nursing home care in order to enter the waiver program. The program began in 1980 as a demonstration project and converted to a 2176 waiver in 1983. During 1985, 3,944 people were served. Person-level data were obtained for client and control groups regarding Medi-Cal expenditures, Medicare costs, and functional and health status. Functional and health variables were used to control for differences between treatment and control groups in the risk factors that influence nursing home use.

The MSSP waiver consisted of a generous service package composed of case management, adult day care, housing assistance for minor repairs, in-home supportive services such as personal care services, respite care, transportation to places where services were delivered, and in-home or congregate meal services. The program was highly attractive to many elderly, unfortunately to elderly regardless of their risk of nursing home entry. The program was administered by the California Department on Aging.

The study found that MSSP services cost less than nursing home care - $350 compared with $1,144 per month in FY1984. Thus, the program must correctly substitute

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[6] For a more detailed discussion of the six case studies, refer to Clinkscale, R. and Vertrees, J. EVALUATION OF MEDICAID SECTION 2176 HOME AND COMMUNITY CARE WAIVERS, Interim Report, Medicaid Program Evaluation Working Paper No. 1.10, Health Care Financing Administration, December 1986; Clinkscale, R. QUALITY OF MEDICAID HOME CARE SERVICES IN VIRGINIA, Medicaid Program Evaluation Working Paper No. 1.12, Health Care Financing Administration, May 1988; and Burwell, Brian, MARYLAND WAIVER PROGRAM FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A CASE STUDY, Medicaid Program Evaluation Working Paper No. 1.13, Health Care Financing Administration, August 1988.

a day of waiver care for a day of nursing home care 30 percent of the time in order to break even or be budget neutral to Medicaid. Our statistical analysis found that only 2.5 percent of MSSP clients would have entered a nursing home in the absence of the waiver (client targeting) and for those who would have entered a home, the MSSP services did little to change this probability (service efficacy). The MSSP was not targeted to persons at extremely high risk of nursing home entry, and when targeting was correct, the waiver services did not prove to be good substitutes for nursing home services.

(b) Georgia Community Care Services Program (CSSP)

The Georgia waiver originated as a demonstration program in 1976 and serves an aged and chronically ill population throughout the State. The CSSP became a waiver program effective October, 1981. The demonstration phase of the Georgia program was evaluated and found to be lacking in client targeting; i.e., rates of nursing home entry for the treatment and control groups were found to be equal at 15 percent over the two year follow-up period. In reviewing Georgia's application for a 2176 waiver, HCFA expressed concern about the lack of previous cost-effectiveness as a demonstration. Georgia proposed to improve client targeting by more carefully screening each applicant and to cap waiver costs at 75 percent of nursing home costs.

The Georgia waiver program offered three classes of services. The least intensive was adult day rehabilitation (adult day health) offered to disabled elderly who had problems living on their own and provided a place during the day for health observation, social interaction, a warm lunch meal, and physical and occupational therapy. Transportation to and from a community center was provided. The middle service level is home delivered services for those elderly not functional enough to get to adult day rehabilitation centers. This level offered personal care services, skilled nursing services, physical and occupational therapies, home health aide services and medically-related transportation. The most intense level is alternative living services (ALS) or 24 hour supervision, medically-oriented personal care and health-related support services in a residential setting other than the client's own home. Basically, this support level was a short-term place to live and be cared for until the clients permanent living arrangement could be made suitable.

Our case study compared the experience of over 1,000 waiver recipients in late 1981 and 1982 with that of a community control group established for the earlier demonstration. Most of the waiver recipients were elderly black females, 20 percent were over the age of 85, and most suffered from multiple chronic functional impairments. All waiver recipients met nursing home admission criteria. Health status assessments were available on both groups, and Medicaid and Medicare claims data were linked to identify comparative utilization and expenditure profiles. The average cost of waiver services in Georgia during 1982 was $172 per month compared with average monthly nursing home costs of $727. In other words, each person correctly enrolled might save enough to pay for three others who would have never gone to a nursing home or who went to a nursing home in spite of receiving services. Our analysis matched waiver and controls on demographic, health and degrees of functional impairment.

Our findings regarding client targeting were somewhat encouraging in that individuals enrolled in the waiver program had a 30 percent chance of entering a nursing home during the waiver period (30 percent of the control group enter a home). This percentage is much higher than the 2.5 percent found in the California MSSP study. However, additional findings showed that the waiver services were not useful in delaying nursing home entry; i.e., both waiver and controls were equally likely (30 percent) to enter a nursing home. About 30 percent of both waiver and control groups

entered a nursing home over the period of analysis. Therefore, the cost of Georgia waiver services were an add-on to Medicaid since there were no offsetting savings in nursing home expenditures.

(c) California In-Home Medical Care (IHMC) Waiver

This waiver targets in-home nursing services to severely disabled individuals who are often ventilator dependent small children at high risk of long-term hospitalization. Most recipients are extremely ill, often comatose. Mortality accounts for most program terminations. Retardation is prevalent for the target group due to brain damage at birth. During 1982 there were about 115 recipients in the waiver program. California's waiver application projected Medi-Cal savings approaching $15,000 per recipient per month since hospital costs were $30,000 per month and the cost of in-home nursing services were projected to be $15,000 per month. At the same time, the in-home nursing would enable the recipient to live at home with family instead of at the hospital.

Our evaluation design involved a simple comparison of Medi-Cal expenditures 3-6 months before and after entry to the waiver program for a sample of 19 recipients. The sample is regarded as representative of typical waiver recipients. The average cost of waiver services was found to be $218 per day, mostly to pay for 16-hour nursing services. Average total Medi-Cal expenditures before waiver entry were $10,138 per month, compared to $12,125 after entering the waiver program. This is a very different outcome than projected in the waiver application. Based on the sample examined it would seem that the level of hospitalization prior to waiver entry was much lower than projected and, unexpectedly, the level after entry was higher. Twelve of the 19 recipients in the sample had monthly Medi-Cal costs of less than $5,000 in the pre-waiver period. This reinforces the finding that substantial numbers of waiver recipients were already living at home during six months prior to waiver entry rather than at hospitals.

The average increase in Medi-Cal costs after waiver entry was not, however, found to be statistically significant due to high variances in the cost data. The findings do suggest that contrary to expectations, the IHMC waiver program probably does not result in the savings to Medi-Cal projected in the waiver application. Our qualitative review of the program suggests that quality of care for the homebound recipients is excellent.

(d) Virginia Personal Care Services Waiver

The Virginia personal care waiver was chosen for case study because of the way in which eligibility for waiver services is linked to a statewide mandatory nursing home preadmission system. This preadmission screening (PAS) program is one of the oldest in the nation and is believed to be one of the most effective in channeling nursing home applicants to the most appropriate and desirable care setting. The major study objectives were to understand how the PAS program was used to base client targeting into the waiver, to determine how well the targeting system worked, and to fully explore waiver quality of care and the role played by Virginia's quality assurance procedures.

Case study methods included review of Virginia's waiver applications and annual reports, interviews with State Medicaid waiver staff, and site visits to a stratified random sample of nine providers. At the provider site, structured interview guides were used to interview the agency administrator, nurse supervisors, personal care aides and visits to client homes to get a first-hand understanding of the appropriateness and quality of the personal care services. Most of the personal care

aide interviews were conducted in the home of their patients. In all cases, viewpoints of patient informal caregivers (typically a family member) were solicited. Personal interviews were conducted with 8 program administrators, 9 RN nurse supervisors, 3 other RNs, 18 personal care aides and 17 waiver recipients in their homes. Interviews were also conducted with Medicaid utilization review staff.

The Virginia waiver serves approximately 3,000 recipients annually at a FY86 cost of $10.5 million, or $3,500 per recipient. The only service offered under the waiver is personal care. Personal care generally includes help with bathing, meal preparation, household chores, and personal hygiene. The personal care aide typically comes into the patient's home for four hours per day, five days a week. The schedule varies with the needs of the client and informal caregivers. Most recipients had strong informal caregiver support. The presence of the personal care aide made it possible for the informal caregivers to continue working, care for children, and otherwise keep the family together.

Quality assurance in the Virginia system begins with the PAS program where emphasis is put on targeting waiver services only to those who are at high risk of nursing home entry. Geriatric assessments are conducted using standardized instrumentation. PAS screening teams are both community and hospital based, physician supervised and typically composed of a public health nurse and a social worker. Where appropriate, individuals are referred to a nearby certified personal care services provider for an additional assessment and service delivery. Provider RN nurse supervisors do monthly in-homes visits to check on patient condition and coordinate the plan of care with the patient's personal services aide. State QA review coordinators conduct on-site desk reviews of all waiver recipients every six months and annually, they conduct in-home reviews.

Although the rigor of the Virginia's overall quality assurance structure and processes are impressive, the most significant finding from the case study is the quality of the people working within the service delivery system. The expertise and dedication of the Medicaid staff who administer the program is exemplary. Although wages for nurses and personal care aides in Virginia is relatively low, the level of training and quality of provider nurses and personal care aides was exceptional. Turnover among nurses and personal care aides was relatively low. The PAS system worked very well, client targeting accuracy was found to be 60 percent based on patient/caregiver interviews. This is the highest ever reported by an evaluation study of a home and community care program.

Patient and caregiver interviews indicated that satisfaction with the program was very high. Our judgement as to why the Virginia waiver works so well is due to the rigor of their PAS as a targeting tool, to the rigor of their QA procedures, and to the passion for excellence demonstrated by most everyone from the State staff down to almost every nurse and personal care aide. The program is also administratively simple. Personal care is the only waiver service provided and they do that well.

(e) Maryland Developmental Disabilities Waiver

The Maryland waiver was selected for case study because it is one of the few waivers for the developmentally disabled which is exclusively targeted to persons living in ICF-MRs. Individuals already living in the community cannot enter the waiver. In part a result of this, Maryland waiver recipients are much more severely retarded than in other waivers nationally. The purpose of the case study was to more closely investigate recipient quality of care and to better understand the role played by the waiver in building the Maryland residential care network.

In February 1983 the State signed a consent decree in response to a Federal Justice Department class action suit stating that conditions in several of the existing large scale State institutions were below standard. The court order stipulated that the average daily census at the Rosewood Center, Maryland's largest state-owned facility, would be reduced by 40 percent over a three-year period, the residents were to be relocated to community-based settings. Maryland applied for and used the Medicaid waiver as a means to finance the deinstitutionalization objectives set forth in the consent decree. The original waiver was granted in 1984 and the State has received a renewal for five years (1992). The waiver is managed by the Developmental Disabilities Administration.

The case study entailed study of the Maryland original and renewal waiver application, annual reports, intensive interviews with DDA staff in Baltimore, and site visits to 15 of the 40 residential centers. These providers account for about 60 percent of the 716 waiver recipients.

During 1987-88 waiver year 716 recipients were served at a cost of $25 million dollars, or an annual cost of nearly $35,000 per recipient. This relatively high cost is due to the Maryland residential model of no more than three persons to one living unit. This results in very high room and board costs as well as residential staff costs per unit. Maryland offers four basic services: 1) residential services, 2) day program habilitation services from providers on contract from the residential care unit, 3) transportation services provided by the day program provider, and 4) case management. Maryland contracts with local health departments and private agencies to conduct independent case management and coordination.

The quality assurance system is multi-tiered. First, case managers act as service coordinators and client advocates. They visit the client every couple of months, monitor the provider's implementation of the Individual Program Plan (plan of care), and advocate for services. Second, DDA contracts with the Delmarva Foundation, the peer review organization in Maryland, to conduct annual re-certifications of client eligibility and to ensure that the client is receiving active treatment. Since all waiver providers are also Medicaid providers, they are also monitored by Medicaid inspection of care (IOC) teams. The teams make annual reviews of all waiver clients. Fourth, all residential programs must be licensed and certified by DDA. Licensing and certification teams make annual visits to inspect residential facilities.

Waiver recipients in Maryland are, on average, more severely disabled than in other States. In Maryland, almost 77 percent of recipients are diagnosed as severe to profoundly mentally retarded compared to 49 percent in other waiver programs. Further, 7 percent are not toilet trained, 14 percent cannot walk without assistance, 63 percent cannot dress without assistance and 37 percent cannot communicate verbally. They are also somewhat older. Only 4.3 percent are under age 21, compared to 20.5 percent of all DD waiver recipients. Also, 45 percent are over the age of 40 compared to 25 percent of all waiver recipients nationally.

Several of the older and more established providers expressed some concern that quality has suffered with the rapid expansion of new residential providers in response to the 1983 consent decree and to the waiver implementation in 1984. Most State staff and providers felt that, overall, the quality of life for the recipients has been greatly enhanced by relocating to small residential care homes. If there were a single overriding issue it would be the problem of recruiting and keeping direct care staff to work in residential programs. Every provider had staffing vacancies. The average time on the job for direct care staff was only six months. Everyone agreed that the high staff turnover increased costs and reduced quality.

Providers agreed that quality staff could not be attracted and retained for $5 per hour. Other providers attributed the high residential turnover to job stress and a lack of training and career mobility. Finally, other quality-related concerns were the short supply of behavioral management support services and crisis intervention programs and access difficulties to primary care centers and general hospitals.

There was common agreement that the quality assurance system was not doing a good job of promoting quality. The external monitors, although well intended, simply did not know the clients well enough to make professional judgments about quality of care. One popular notion was that the State scrap the current multi-tiered QA system and invest the savings in professional monitors who could spend more time with the clients. Case management and advocacy components could be likewise bundled into the new "super overseers." Most providers felt that State proposals to expand the program further would be unwise until staffing and quality problems could be cleaned up. One provider summed it up this way: "Quality of care may be less than we would like, but it's a damn sight better than living in an institution."

The State has projected substantial increases in the cost of serving waiver clients. The State is projecting an average annual per recipient cost of close to $45,000 for the projected 160 more new waiver entrants. This cost is becoming closer to ICF-MR costs of $65,000 per year. Should the State decide to reduce fixed costs in the large ICF-MR facilities as occupancy falls, ICF-MR costs per client could drop and threaten the cost-effectiveness test for the waiver.

(f) California Developmentally Disabled Services (DDS) Waiver

The study used a pre-post evaluation design. The study population included all persons who received DDS waiver services in 1983, a total of 594 individuals. For the cost study, only those waiver recipients who were also enrolled in Medicaid in 1981 (prior to implementation of the waiver), who used at least one Medicaid-covered service in 1981, and for whom 1983 Medi-Cal data were available were selected. The sample thus included a total of 488 developmentally disabled persons who were both Medicaid recipients in 1981 and waiver recipients in 1983. The study addressed the question: What did it cost Medi-Cal to serve waiver clients prior to the waiver in 1981 after they were admitted to the waiver (1983)? Detailed claims for waiver services from DDS were linked with Medi-Cal person-level claims for non-waiver services to obtain a complete record of Medicaid utilization and expenditures for the study sample in 1981 and 1983. Person-level data on spend-down liability amounts were used to estimate impacts on Federal SSI costs.

Prior to the waiver in 1981 most of the eventual DDS waiver recipients lived in the California State hospital system, reimbursed by Medi-Cal at ICF-MR rates. Hence, in 1981 the average annual cost to Medicaid, annualized to a full year of Medicaid coverage and inflated to 1983 dollars, was $29,414 as compared to $8,699 in 1983. About $7,000 of this total was for DDS waiver services, the remainder represents non-waiver Medicaid service costs. Thus, the DDS waiver clearly demonstrates that it can be much less expensive to care for the mentally retarded in residential settings than in relatively expensive ICF-MR institutions. This is true even when increased Federal SSI costs are considered.

Based on this pre-post data it would appear that a savings of $10 million had accrued to Medicaid. On the other hand, we found that most of the waiver recipients had been deinstitutionalized well prior to their entry into the waiver program as part of an ongoing statewide effort to transfer mentally retarded patients to a system of State-funded residential care. Thus, it can be argued that potential savings to Medicaid is attributable to the deinstitutionalization program rather than the

waiver. The cost of waiver services would be equivalent to an increase in Medicaid spending.

An additional finding is that the potential $10 million savings to Medicaid at the person-level was probably never realized at the overall Medi-Cal level. Although the number of persons in State institutions declined by 12 percent between 1981 and 1985, the average per-person institutionalized cost increased by 40 percent. Although Medicaid bought fewer days of ICF-MR care, increases in the cost per day appear to have more than offset the potential savings; i.e., overall ICF-MR spending increased. When occupancy rates fell in the State institutions they continued to operate them at about the same cost, and higher costs per patient day were passed on to Medicaid. Our overall conclusion is that it is implausible that the waiver was budget neutral to California's Medicaid program.

3. SUMMARY OF CASE STUDY FINDINGS

The four case studies of A/D waivers in California, Georgia and Virginia suggest that generalizations about how well waiver programs work should be guarded. Firm conclusions can only be drawn from waivers specifically studied. Even then the findings could be flawed given the complexity of the evaluation issues. The A/D case studies (and most of the evaluation research literature) do suggest that client targeting accuracy sufficient to render waiver program budgets neutral to Medicaid is doubtful. There is even some question as to whether the waiver services themselves are appropriate to delay or prevent institutionalization in any significant way. As with any generalization, there are bound to be some exceptions.

The Virginia waiver is a case in point. The Virginia model is to keep the program administratively simple, offer limited services, keep the cost per recipient down, use mandatory preadmission screening, compensate providers for reasonable costs, and employ rigorous quality assurance procedures. The intangible ingredient is to have people everywhere in the delivery system totally dedicated to quality of care. We have learned that these are the determinants of a successful A/D waiver.

The two case studies of DD/CMI waivers in California and Maryland suggest that individuals can be successfully deinstitutionalized. The cost to Medicaid of serving DD/CMI clients is usually considerably less than in ICF-MR institutions. The characteristics of the DD/CMI waiver population suggest that waiver clients are generally younger and less impaired than their cohorts still living in ICF-MRs. It is not clear how effective residential care can be for those cases severely and profoundly retarded. Quality of care in the DD/CMI waivers can be a problem if turnover of residential direct care staff is high. There is also some question as to the real effectiveness of quality assurance models which rely on inspection staff who do not have enough time to get to know the patient personally.

As to the cost-effectiveness of DD/CMI waivers, this depends on how you approach the issue. If States are simply using the waivers to help finance Federal court decrees to deinstitutionalize their large state owned ICF-MR populations, then the DD/CMI waivers in no way could be considered anything but a cost add-on to Medicaid. On the other hand, if the position is taken that the impact of the waivers is to speed up the deinstitutionalization process, waivers having Medicaid per capita costs below equivalent ICF-MR costs will be cost-effective to Medicaid. If other costs of residential care such as SSI payments and food stamps are taken into consideration, cost-effectiveness becomes questionable again. Professionals who administer the waivers are unanimous in feeling that most ICF-MR residents enjoy a higher quality of life in a residential care network where attention is more individualized and emphasis is put on habilitation and maximum independence.

CHAPTER FOUR
SUMMARY AND CONCLUSIONS

The Omnibus Budget Reconciliation Act of 1981 (Section 2176) provision allows the Secretary of the U.S. Department of Health and Human Services to waive certain federal Medicaid rules that would make it possible for people with disabilities to remain at home or in a community noninstitutional setting. The waiver program has been very popular with most States. The waiver makes it possible for State Medicaid programs to gain federal financial participation by making available to individuals wishing to remain at home or noninstitutional setting the same eligibility rules as for nursing home and institutional care residents plus expanded service coverage to include non-medical services such as personal care and homemaker, respite, adult day health, case management, non-medical transportation and "other" services as needed to maintain someone in the community.

This evaluation has addressed the extent to which States have used the waiver authority, the cost-effectiveness of the waivers, the quality of care under the waivers, and the determinants of a successful waiver. The evaluation has investigated national level data using information reported to HCFA by State Medicaid agencies and six case studies were conducted on individual waiver programs.

1. NATIONAL LEVEL STUDIES

Annual data routinely reported to HCFA by State Medicaid agencies is insufficient to profile waiver recipient characteristics, services provided, expenditures, eligibility options chosen, and quality assurance mechanisms. This evaluation surveyed all active State waivers for fiscal years 1984-86 in order to fill in missing information. A second source of nationwide data was annual statistics reported to HCFA related to nursing home and ICF-MR use and expenditures. That data base was used to investigate whether use and expenditure rates in States having waivers was any different than for States not having a waiver. The results of these analyses are described below. A third source of national level data was the annual reports required by HCFA on each waiver program. These reports (HCFA Form 372) contain data on total waiver expenditures, by waiver service and data Medicaid costs of institutional care for waiver cohorts. The reports also gather information on waiver unduplicated recipient counts and days of care.

(a) Annual State Surveys

The major target groups for the home and community-based care waivers are the aged and disabled and the developmentally disabled/chronically mentally ill (DD/CMI). Over 95 percent of the (DD/CMI) group represent the mentally retarded. State Medicaid agencies are free to tailor their waiver programs to individual target groups, offer the program in selected areas of the State, and select the service package that fits the needs of their long term care population. Congress did add the constraint that States must demonstrate to the Secretary DHHS that Medicaid per capita costs for waiver recipients will not exceed those for institutional care residents.

By September 30, 1986 there were 83 active waiver programs in more than 40 States; 43 A/D waivers and 40 DD/CMI waivers. Approximately 109,628 people were served, 82,981 in the A/D waivers and 26,647 in DD/CMI waivers. Altogether, about

$385 million was spent on waiver services, 60 percent of which was spent on DD/CMI waivers. The average annual cost per recipient was $8,281 for DD/CMI and $1,982 for the A/D recipients. For the A/D waivers, most of the funds were spent on personal care and homemaker services while for DD/CMI most of the money was spent on residential care staff and habilitation day programs.

Most people entering waiver programs do not come from institutions, rather they already live at home or in the community and enter the program from that point. Less than 5 percent of A/D recipients enter waivers from nursing homes and only about 35 percent of DD/CMI recipients enter the waiver from an ICF-MR or other institution. Thus, the waiver program has not resulted in an emptying of long term care institutions in any significant way.

(b) Aggregate Use and Expenditure Rates

Analysis of data available on State nursing home use and expenditure trends indicates that the waivers have not made a statistical difference on overall national trends for Medicaid-funded nursing home and ICF-MR use and expenditures. This may be because waiver recipient numbers are still relatively small compared with their cohorts still in institutional care. For example, the penetration rate for the A/D waivers has only recently risen to 7.3 percent, the DD/CMI rate is 23.3 percent. The A/D waiver penetration rate is probably too low to make a statistically significant difference in nursing home use rates across waiver States. We were surprised that the DD/CMI waivers made no difference. If the waivers had been successful in reducing ICF-MR use we would have expected to be able to measure the effect. Inspection of national ICF-MR use data indicates that use is on the decline nationwide due to court orders during the mid-1970s to discharge any institutionalized persons who could live safely in less restrictive residential settings. States having DD/CMI waivers did not have rate reductions greater than non-waiver States.

(c) State Annual Reports to HCFA

Analysis of available State annual reports to HCFA (Form 372) indicated that Medicaid expenditures are lower for waivered clients as compared to cohorts in nursing homes other institutions. Among the reporting States, the average annual total Medicaid expenditure per full person-year of A/D waiver coverage was $8,273 as compared to $12,435 for a year in a nursing home setting. This represents a potential savings of $4,162 per year of coverage; or a one-third reduction.

Data reported for the MR/DD group show greater potential for cost savings; e.g., $11,027 per year for waivered recipients compared to $25,453 per year for ICF-MR residents; a reduction of almost 60 percent per person-year of coverage. Unfortunately, these data were available on only a small number of waivers (eight second year waiver reports approved by HCFA) and may not be completely representative. They do, however, support the notion that home and community care can be considerably less expensive for Medicaid than institutional care.

This analysis of potential savings must be discounted by two considerations. First, several key assumptions must be true before the potential savings will be realized. The general conclusion from prior research and the case studies conducted as part of this evaluation is that these assumptions are not likely to be met. Second, the HCFA Form 372 data has come under some criticism from the General Accounting Office as containing data of questionable validity and reliability. Both of these caveats render our analysis of the Form 372 data of limited value.

2. SUMMARY OF CASE STUDY FINDINGS

The four case studies of A/D waivers in California, Georgia and Virginia suggest that generalizations about how well waiver programs work should be guarded. Firm conclusions can only be drawn from waivers specifically studied. Even then the findings could be flawed given the complexity of the evaluation issues. The A/D case studies (and most of the evaluation research literature) do suggest that client targeting accuracy sufficient to render waiver program budgets neutral to Medicaid is doubtful. There is even some question as to whether the waiver services themselves are appropriate to delay or prevent institutionalization in any significant way. As with any generalization, there are bound to be some exceptions.

The Virginia waiver is a case in point. The Virginia model is to keep the program administratively simple, offer limited services, keep the cost per recipient down, use mandatory preadmission screening, compensate providers for reasonable costs, and employ rigorous quality assurance procedures. The intangible ingredient is to have people everywhere in the delivery system totally dedicated to quality of care. We have learned that these are the determinants of a successful A/D waiver.

The two case studies of DD/CMI waivers in California and Maryland suggest that individuals can be successfully deinstitutionalized. The cost to Medicaid of serving DD/CMI clients is usually considerably less than in ICF-MR institutions. The characteristics of the DD/CMI waiver population suggest that waiver clients are generally younger and less impaired than their cohorts still living in ICF-MRs. It is not clear how effective residential care can be for those cases severely and profoundly retarded. Quality of care in the DD/CMI waivers can be a problem if turnover of residential direct care staff is high. There is also some question as to the real effectiveness of quality assurance models which rely on inspection staff who do not have enough time to get to know the patient personally.

As to the cost-effectiveness of DD/CMI waivers, this depends on how one approachs the issue. If States are simply using the waivers to help finance Federal court decrees to deinstitutionalize their large state owned ICF-MR populations, then the DD/CMI waivers in no way could be considered anything but a cost add-on to Medicaid. On the other hand, if the position is taken that the impact of the waivers is to speed up the deinstitutionalization process, waivers having Medicaid per capita costs below equivalent ICF-MR costs will be cost-effective to Medicaid. If other costs of residential care such as SSI payments and food stamps are taken into consideration, cost-effectiveness becomes questionable again. Professionals who administer the waivers are unanimous in feeling that most ICF-MR residents enjoy a higher quality of life in a residential care network where attention is more individualized and emphasis is put on habilitation and maximum independence.

There are several critical limitations to the Section 2176 analysis. First, we have conducted only six case studies of waiver programs; hardly enough to be statistically significant, regardless of the findings. Second, most waivers have been in effect for less than five years from the time of the analysis. The real effect of the waivers on State long-term care delivery and financing may take more time. Finally, the suspected lack of budget neutrality does not necessarily mean that the Section 2176 program is bad Federal policy. The value of the waiver services to recipients and their families may by far outweigh any added Federal costs.

3. GENERAL CONCLUSIONS

It is doubtful if many aged and disabled waivers are cost-effective due mainly to the difficulty with targeting eligibility to individuals who, but for the waiver, would be in nursing homes. This is the conclusion drawn from case studies in California and Georgia. On the other hand, the Virginia case study suggests that linking the waiver program with mandatory preadmission screening for nursing homes may well improve client targeting so that a waiver program can be at least budget neutral to Medicaid. This general conclusion is similar to other evaluation research related to the cost-effectiveness of home care.

As to the cost-effectiveness of DD/CMI waivers, this depends on how one approaches the issue. If States are simply using the waivers to help finance Federal court decrees to deinstitutionalize their large state owned ICF-MR populations, then the DD/CMI waivers in no way could be considered anything but a cost add-on to Medicaid. On the other hand, if the position is taken that the impact of the waivers is to speed up the deinstitutionalization process, waivers having Medicaid per capita costs below equivalent ICF-MR costs will be cost-effective to Medicaid. If other costs of residential care such as SSI payments and food stamps are taken into consideration, cost-effectiveness becomes questionable again. Professionals who administer the waivers are unanimous in feeling that most ICF-MR residents enjoy a higher quality of life in a residential care network where attention is more individualized and emphasis is put on habilitation and maximum independence.

Quality assurance in waiver programs is likely to be very good. Special efforts are made by States to monitor vulnerable individuals very carefully. Case managers are often used to help plan and monitor client progress against structured plans of care. In most waiver programs, clients are reviewed at least every six months and typically seen in their homes at least once a year.

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